

Depression, Burden, and Self-Efficacy among Caregiving Parents of Children with Cancer

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Abstract:

Background: Cancer is stigmatized in Egypt, where there are many misconceptions associated with having cancer. Most people think that cancer is the death penalty. **The aim of the study** is to determine the degree of burden, depression, and self-efficacy among caregiving parents of children with cancer. **Design:** A descriptive correlational research design was utilized. Setting: The study was carried out at the outpatient clinic of Sporting Students Hospital which is affiliated with the Health Insurance Organization, Ministry of Health and Population. The hospital has an outpatient clinic for children suffering from cancer. **Sample:** Subjects of the present study consist of 200 caregiving parents of children with cancer who were recruited from the outpatient clinics of Sporting Students Hospital. **Tools of data collection: Tool 1:** Caregiver socio-demographic and clinical data structured interview schedule. **Tool 2:** Caregiver Burden Inventory (CBI). **Tool 3:** Caregiver Self-Efficacy Scale (CaSES). **Tool 4:** Center for Epidemiologic Studies Depression (CES-D) Scale. **Result:** About three quarters of the subjects (72.5 %) were mothers, the mean score percent of total burden among the studied caregiver parents was 63.59±13.94% reflecting high degree of burden, in which the majority of them (96.0%) were at high risk for burn out, the mean score percent of the self-efficacy among the studied caregiver parents was 52.34± 12.02 %, showing that the majority of the studied caregiver (81.0%) had moderate level of self-efficacy and 99.0% of the studied care giver parents had depression with the mean score percent of 61.84±15.87 reflecting a very high level of depression. **Conclusion:** The great majority of the studied cares giving parents were at high risk for burn out and almost all of them were depressed. They tend to have high scores for both burden and depression. In addition, the majority of them had a moderate level of self-efficacy. Caregivers' burden significantly positively correlates with depression. As well, the more self-efficacy they have, the less their burden and depression. **Recommendation:** Based on results, family caregivers (FCs) have to be included in the plan of child care. Also, psychiatric health care nurses have to emphasize the issue of supporting family caregivers to improve their management of symptoms including those less visible such as emotional and communication issues.

Keywords: Cancer, Caregiver parents, Depression, Self-efficacy and burden.

Introduction

Cancer is a life-threatening illness that may have some similarities to chronic illness in their longevity, but the prognoses are often terminal. The impact of the caregiving process is great; the family caregivers' psychological health can deteriorate and a low level of self-efficacy is presented, due to that, the caregiving role restricts their social, personal, and vocational desires, also they are not quite trained in care giving and this leads to additional burden (Lewandowska, et al., 2020).

Caregivers of patients with cancer trying to modify their lifestyles to accommodate the child's needs, this disturbance in the family functioning has been associated with higher levels of depression. If the caregivers have a sense of self-efficacy this may protect against the adverse effect of caregiver burden on their depressive symptoms (Zavagli V, et al., 2022).

Cancer is the second leading cause of death in children and the primary cause of death from diseases (World Health Organization., 2018). Diagnoses of childhood cancer have an

enormous impact on the affected children and their families. They are confronted with a life-threatening disease that usually implies extensive treatment with negative side effects and the risk of negative long-term consequences (Long, K. A, 2018). This affects the entire family system, generating anxiety and altering communication patterns and relationships among its members (Thomas, P. A., 2017). After the diagnosis of cancer is confirmed, the next step to go through is the treatment phase, parents watch their child's hair fall out, watch the loss of his physical ability, and become very weak that he can no longer perform basic needs independently. These situations have a tremendous emotional impact on the family system and the extra financial burden on the already stressed family. Even after the end of treatment, the parents are preoccupied with the fear of recurrence, so they become overprotective, and this attitude prevents an early return to the social normality of the family (Xu, L., 2017).

Cancer is increasingly becoming a chronic disease, which brings considerable needs and problems to both patients and caregivers. The current health policy trend is to downsize acute-care hospitals and to transfer a greater portion of care to the home, where family members form a substantial part of the care system. This unpaid assistance, which is provided to someone who is to some degree physically or mentally incapacitated and needs help, is described as informal or family caregiving (Goren A, 2014).

Caregiver parents are often frightened and upset by the diagnosis of their child, but they have an additional responsibility of trying to support their child as they go through this difficult time in the process of providing support, caregiver parents are often overlooked and have no one to turn to with their own concerns (Koch, K, 2018). As cancer management becomes more complex, the patients' multidimensional needs have expanded from treatment monitoring and symptom management to emotional and financial support and assistance with personal care (Bajwah, S, et al., 2020). As a result of increased responsibilities, family caregivers often experience increased psychological

distress, pressure, and health-risk behaviors and a decline in physical health, personal welfare, and mental health as a result cancer cause a caregiver burden (Schulz, R., 2008).

Given et al (2004) defined caregiver burden as a multidimensional bio-psychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill (Given, B., al., 2004). Caregiver burden has certain types, the first is the objective burden, which refers to the practical problems, which the caregiver encounter while caring for a sick child. It may be physical or financial as a side effect and complication management, traveling or transportation and money management. On the other hand, the subjective burden refers to the grief, fear, guilt, anger, and other negative emotions that caregivers experience in response to the sickness of their child. The last type is the iatrogenic burden, which is attributable to a dysfunctional mental health system and to the attitudes of some mental health professionals, which leave a legacy in terms of disinterest in the needs of the caregivers and failure to provide family services (Liu, Z., 2020).

Family caregivers often go beyond their abilities and circumstances trying to be the best possible caregivers. Unfortunately, many of these heroic caregivers are risking their own personal well-being, and sometimes their families' life in this process. Many caregivers are not fully aware of the short and long-term consequences of 'doing it all alone because they are so overwhelmed with managing their daily tasks and responsibilities (Leow M, 2014). A study of Australian caregivers of children with cancer revealed that 69% of the studied subjects reported fatigue, 69% reported decreased ability to concentrate, 58% reported decreased motivation, 46% reported affected relationships, and 42% reported decreased ability to perform usual activities (Ugalde, A., et al., 2019).

As parents increasingly play many roles in the care of the child with cancer, these roles include, providing emotional support, monitor symptoms, comply with medical treatments, deal with side effects, and communicate with health care professionals (18). To carry out their

vital role, caregivers must have a high level of self-confidence and self-efficacy (Ha, J. 2010).

Concerning caregiving, self-efficacy theory suggests that individuals with higher levels of self-efficacy will have a greater level of success in completing caregiving tasks, lower levels of psychological and physical illness, reduced rates of burnout, and greater levels of wellbeing than those with low levels of self-efficacy (Levesque, J. 2018).

Self-efficacy is the confidence in one's ability to perform a specific behavior or task. Most caregivers of patients with cancer are family members, who may not be prepared for, or have the resources and energy to meet the needs of the patient. When caregivers face caregiving demands, those with low self-efficacy beliefs focus on negative aspects of the situation including their personal deficiencies, the difficulties of the task, and the negative consequences of failure. The focus on negative cognitions reduces motivation to initiate an activity and leads to negative affective states including depression, anxiety, and anger (Northouse L, et al., 2012). Caregiver depression is a mood disturbance that may develop over time because of the burden of providing care.

Depression may emerge when coping mechanisms are inadequate. It is manifested by feelings of loneliness, isolation, fearfulness, and being bothered, and may have a somatic component such as decreased appetite, fatigue, and insomnia (Sun, N., et al., 2020). Caregivers seldom use any form of mental health services to deal with their own depression, and this puts them at risk for long-term health problems. An Egyptian study of caregiving parents showed that more than 66% had a high level of depression, almost 60% had poor relations, and nearly 66% of them had high social isolation (Schulz, R., 2008).

Cancer and its treatment often change day-to-day life for the whole family. It may cause financial stress and bring up fears of losing what's good in life. Some people will start to look more carefully at what they believe in, their work, and the way they will live if more changes are needed. Having cancer is hard, and getting through it can be a very complicated process (Gibbins J, 2012).

The significance of the study

The professional psychiatric nurse has an important role in providing help and support for caregivers to overcome their life problems, cope with the challenges they face, and enhance their life. This can be done through assessing the caregiver's degree and types of burden, and level of caregivers' self-efficacy and depression (Schulz R, 2016). This process can be a database for planning psycho-educational interventions, skills training interventions that focus on the development of coping strategies, communication techniques, and problem-solving skills. These services can be provided to caregivers to manage their own physical and emotional health needs, gain confidence in their caregiving role, maintain their social support system, and access resources to decrease the caregiving burden. In addition, these data can help in planning therapeutic Counseling programs that focus on the development of a therapeutic relationship to address concerns related to cancer or caregiving (Demiris, G., 2010).

The study aim to:

The present study aims to determine the degree of burden, depression and self-efficacy among care giving parents of children with cancer.

The research questions:

1. Do caregiving parents of children with cancer suffer from depression?
2. What are the degree of burden and level of self-efficacy among caregiving parents of children with cancer?
3. Is there a relationship between the degree of burden, level of self-efficacy, and presence of depression among caregiving parents of children with cancer?

Subject & Methods

Research Design:

A descriptive correlational research design was used to conduct this study.

Setting:

The study was carried out at the outpatient clinic of Sporting Students Hospital in Alexandria, which is affiliated with the Health Insurance Organization, Ministry of Health and Population. The hospital has an outpatient clinic for children suffering from

cancer. Oncology clinic serves children with cancer aged from one day up to 16 years. Subjects:

According to the Epi Info 7 sample size estimation program, the sample size required for this study is 168. This number was calculated using the following parameters: acceptable error of 5%, confidence coefficient of 99%, and expected frequency of 50%.

By using the purposive sample technique to select the study sample the study consisted of 200 caregiving parents of children with cancer who were recruited from the outpatient clinics of Sporting Students Hospital and met the following inclusion criteria:

- Either child's mother or father is directly involved in the child care.
- Their children already started the treatment for at least two weeks.
- Their children are free from other medical diagnoses.
- Accepting to participate in the study.

Tools: In order to fulfill the objectives of the present study, data were collected using the following tools:-

Tool (I): Caregiver socio-demographic and clinical data structured interview schedule:

This tool was developed by the researchers after reviewing the related literature. It has data about the caregivers' socio-demographic characteristics and caregiving processes such as caregiver's age, kinship's degree, educational level, occupation, residence, marital status, income, housing, and presence of physical illness.

Tool (II): Caregiver Burden Inventory (CBI):

This tool was designed by Novak & Guest (1989) as a multi-dimensional self-reported questionnaire measuring caregiver burden. It consists of a 24-item Likert format scale. The scale measures 5 dimensions of caregiver burden namely: Time dependence burden (5 items), Developmental burden (5 items), Physical burden (4 items), Social burden (5 items), and Emotional burden (5 items). These five dimensions are rated on a 5 point Likert scale which ranges from 0 (never) to 4 (nearly always). All of the scores on the 24-item

are summed to have a total score that ranges from 0– 96 in which a score of 0–23 indicating no need for assistance, a score of 24–35 indicates a need to seek some form of respite care, a score of 36 and more denotes a risk of “burn out” and reflecting a greater degree of burden.

In the current study the Cronbach's alpha value is 0.93 for the whole CBI scale, and for time dependence burden, developmental burden, physical burden, social burden, and the emotional burden was 0.93, 0.83, 0.92, 0.85, and 0.93 respectively.

Tool (III): Caregiver Self-Efficacy Scale (CaSES):

This tool was designed by Ugalde et al. (2013), to assess self-efficacy in caregivers of people with advanced cancer; the scale includes 21 items reflecting four subscales namely: Resilience (6 items), Self-Maintenance (6 items), Emotional Connectivity (5 items), and Instrumental Caregiving (4 items). The scale is rated on a 4-point Likert scale ranging from 0 (not at all confident) to 3 (very confident). The scores on the 21-items are summed to have a total score that ranges from 0-63. A score ranging from 0-20 indicates a low level of self-efficacy, a score ranging from 21-41 indicates a moderate level of self-efficacy, and a score ranging from 42-63 indicates a high level of self-efficacy. The current study revealed that the CaSES showed good internal consistency explained by the Cronbach's alpha value that was 0.82 for the whole scale, and is 0.82, 0.79, 0.81, and 0.77 for Resilience, Self-Maintenance, Emotional Connectivity, and Instrumental Care giving respectively.

Tool (IV): Center for Epidemiologic Studies Depression (CES-D) Scale:

The Center for Epidemiologic Studies Depression Scale (CES-D) was developed by Radloff (1977) for the general population. The scale is the self-reported measurement to assess symptoms associated with depression experienced in the past week. The scale includes 20 items reflecting some areas of depression, i.e. depressed mood, somatic complaints, positive affect, and interpersonal problems (Radloff, L. S. (1977)). The responses are rated on a 4-point Likert scale ranging from 0 (rarely or none of the time) to 3 (most or all of

the time). Four items (4, 8, 12, and 16) are reversely scored. Total scores can range from 0 to 60, in which a caregiver with a score of 16 or more is considered depressed. The current study revealed that the CES-D showed good internal consistency explained by Cronbach's alpha value is 0.89.

Methods

The study was carried out according to the following sequence:

Preparatory phase:

- The study plan was revised and approved by the Faculty of Nursing Ethical committee for Scientific Research, Alexandria University.

- The approval of the Research Ethical Committee, the Central Directorate of Research & Health Development in Cairo, the Ministry of Health and the Health Insurance Organization in Alexandria were also secured.

- An official approval was obtained from the director of Sporting Students Hospital in Alexandria.

Preparation of the study tools:

- Caregivers and children socio-demographic and clinical data structured interview schedule was developed by the researcher after reviewing the related literature.

- Arabic translation of the study tools namely Caregiver Burden Inventory CBI, Caregiver Self-Efficacy Scale CaSES, and The Centre for Epidemiologic Studies Depression Scale CES-D.S was done.

- The translated study tools will be tested for content validity by a jury composed of seven experts in the psychiatric field. Modifications were done accordingly until it proved to be valid.

- Reliabilities of the translated tools CBI, CaSE.S, and CES-D were tested on a sample of 20 care giving parents of children with cancer using the Cronbach's alpha test. The tools proved to be reliable (Cronbach's alpha = 0.93, 0.82, and 0.89 respectively).

- A pilot study was carried out on 20 caregiving parents from the outpatient clinics of Sporting Students Hospital in order to assess the clarity and applicability of the tools and a few modifications were done. Caregivers who

participated in the pilot study were excluded from the study sample.

☒ Data collection:

- Each caregiving parent of children with cancer who meet the inclusion criteria was involved in the study until the required number of the subjects was achieved.

- The caregiving parent was interviewed individually after establishing a trusting rapport with him and explaining the aim of the study and obtaining informed oral consent. Subjects were ascertained that any obtained data will be confidential and their privacy will be assured.

- The researcher visited the outpatient clinic 3-4 days/week.

- Every interview with each caregiving parent consumed from 45 to 60 minutes.

- The clinic works from 9:00 am to 12:00 pm, five days/week (from Sunday to Thursday).

- Data were collected over a period of 7 months, starting from October 2015 to April 2016.

Ethical considerations:

Throughout the study process:

- Informed oral consent was obtained from each caregiver after explaining the purpose of the study.

- Caregiver's privacy and anonymity were respected.

- Data confidentiality was assured.

Statistical analysis:

Data were fed to the computer and analysed using IBM SPSS software package version 20.0. Qualitative data were described using numbers and percentages. Quantitative data were described using range (minimum and maximum), mean, and standard deviation. The significance of the obtained results was judged at the 5% level.

The used tests were:

- Student t-test: For normally quantitative variables, to compare between two studied groups

- F-test (ANOVA): For normally quantitative variables, to compare between more than two groups.

• Pearson correlation coefficient test (r): Was used to correlate between two quantitative variables.

Limitation of the study

The study was conducted in one hospital (Sporting Students Hospital) instead of two hospitals due to administrative barriers in El Shatby Pediatric hospital.

Results

Table (1) presents the distribution of studied caregiver parents according to their socio-demographic characteristics. In relation to the degree of kinship to the child, about 72.5 % were mothers. As regards age, 48.5% of the caregivers were in the age group ranging from 35 to less than 45 years, with a mean age of 36.42 ± 6.20 years. Regarding marital status, 91.5% were married and 56.0% were living in urban areas. Concerning the educational level, 34.0% had a university education, 23.5% had secondary education and the rest 19.5% were illiterate. In relation to occupation, 53.0% were housewives, the studied caregivers 36.5% were employees, and 10.5% had free jobs.

Table (2) presents the distribution of studied caregiving parents according to their family history and caregiving process. Concerning the family history of cancer, the majorities (90.5%) of the caregivers do not have a family history of cancer and only (9.5%) of caregivers have family histories of cancer. Around half the studied subjects (48.4%) reported that the caregivers' spouse was the people who shared responsibilities with him, then the oldest daughter (21.3%), and then the caregivers' father/mother (14.2%). The table shows that the issues bother the caregiver in the caring process. More than half (59.5%) of the studied caregivers were about side effects after the dose of chemotherapy, followed by 24.0% who reported that the child illness has an impact on their personal needs and 18.0% who reported that fear of not curing or death was the most concerns to them during caregiving process. As regards coping with bothering issues.

Figure (1) illustrates the distribution of the studied caregiver parents according to the presence of depression. It shows that 99.0% of the studied caregiver parents had depression with the mean score percent of 61.84 ± 15.87 .

Figure 2 and 3 illustrates the distribution of the studied caregiver parents according to their overall burden and overall self-efficacy. It portrays that the total mean score percent of the burden was 63.59 ± 13.94 . It can show that all the studied caregiver (100%) parents have burden as the majority of them (96.0%) were at high risk for burnout, and only 4.0% of the studied caregivers were in need to seek some form of respite care. On the other hand, the total mean score percent of the self-efficacy was 52.34 ± 12.02 %, where 81.0% of the studied caregivers had a moderate level of self-efficacy, and 15.0% of them had a high level of self-efficacy.

Table (3) represents the relation between burden, depression, self-efficacy, and parent caregivers' socio-demographic characteristics. The table shows a significant relationship between parent caregivers burden and their degree of kinship to the child, caregiver's age, occupation, the impact of childhood illness on parent's job, and their income ($p < 0.001$, $p < 0.001$, $p < 0.001$, and $p = 0.030$ respectively). It is noticed that mothers' burden total mean (65.27 ± 11.64) was higher than fathers' burden total mean score, indicating that mothers had a higher burden than fathers.

Concerning self-efficacy, there is a significant relationship between self-efficacy and the degree of kinship to the child, and parent's occupation, where p values were $p < 0.001$, and $p = 0.001$ respectively. It was noticed that mothers caregivers have a lower total mean of self-efficacy than fathers, as well as, housewives caregivers have the lowest total mean score of self-efficacy, indicating lower self-efficacy.

Table (4) represents the relations between burden, depression, self-efficacy, and parent caregiver's family history and caregiving process. Concerning burden, the table shows a significant relationship between overall burden and sharing responsibility with a caregiver, issues that bother the caregiver in the caring process, and caregiver's coping ways with bothering ($P = 0.009$, $P < 0.001$, and $P < 0.001$ respectively).

Regarding depression, there is a significant relationship between depression and family history with cancer ($P = 0.038$). A

significant relation was found between caregivers' depression and their coping ways with bothering issues ($P \leq 0.001$).

As regard self-efficacy, sharing responsibility with caregiver parent is significantly related to parent caregiver s' self-efficacy ($P = 0.018$), the caregivers who share their responsibilities with their spouse obtain a higher total mean score of self-efficacy (35.12 ± 8.07). Regarding issues that bother the caregivers in the caring process, it is statistically

significant with caregiver parents' self-efficacy ($P = 0.001$).

Table (5) represent the correlation between parent caregiver's overall self-efficacy, overall burden, and depression, it shows there is a negative significant correlation between caregivers' overall self-efficacy, overall burden and depression in which ($r = -0.366$, $p < 0.001$ and $r = -0.315$, $p < 0.001$) respectively, while there is a positive significant correlation between overall burden and depression ($r = 0.759$, $p < 0.001$).

Table (1): Distribution of studied sample caregiver parents according to their socio-demographic characteristics:

Socio- demographic data of caregiver parents	No. (n=200)	%
The degree of kinship to the child		
- Mother	145	72.5
- Father	55	27.5
Age		
- < 25-	78	39.0
- 35-	97	48.5
- 45- 51	25	12.5
Min – Max	22.0 – 51.0	
Mean \pm SD	36.42 \pm 6.20	
Marital status		
- Married	183	91.5
- Widow	15	7.5
- Divorced	2	1.0
Educational level		
- Illiterate	39	19.5
- Read & write / Primary	46	23.0
- Secondary school	47	23.5
- University education	68	34.0
Occupation		
- House Wife	106	53.0
- Employee (Private-Governmental)	73	36.5
- Free job	21	10.5
Residence		
- Rural	88	44.0
- Urban	112	56.0
Housing		
- Living with extended family	30	15.0
- Living with nuclear family	170	85.0
Income		
- Enough	177	88.5
- Not enough	23	11.5

Table (2): Distribution of studied caregiver parents according to their family history and care giving process

Caregiver parents data	n=200	%
Family history with cancer		
- No	181	90.5
- Yes	19	9.5
Sharing responsibility with caregiver (n=155)		
- The spouse	75	48.4
- Eldest daughter	33	21.3
- Caregivers' father / mother	22	14.2
- Caregivers' brothers / sisters	20	12.9
- Relatives	11	7.1
Issues bother the caregiver in caring process		
- Side effects of chemotherapy	119	59.5
- The impact on the personal needs of caregiver	48	24.0
- Fear of not curing or death	36	18.0
- Negative impact on caregiver's time	34	17.0
- Lack of improvement	33	16.5
- Child's behaviour (violence and stubbornness....)	30	15.0
- Child's Sadness	8	4.0
Coping with bothering issues		
- Crying and want to be alone	105	52.5
- Aggressive behaviours (shouting , hitting, quarrelling)	58	29.0
- Read Quran, praying	55	27.5
- Leaving the home	28	14.0
- Smoking	5	2.5

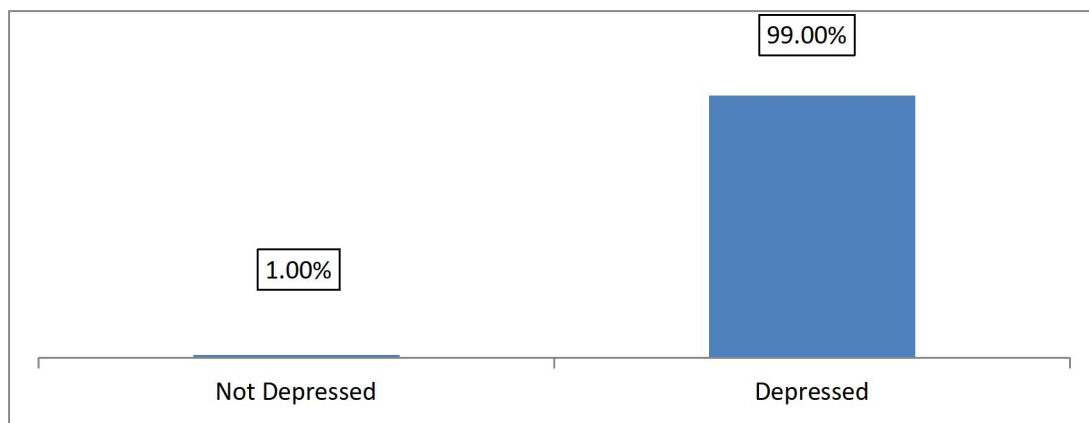


Figure (1): Distribution of the studied caregiver parents according to presence of depression. (Mean score = 37.11±9.52) - (Total mean score percent=61.84±15.87).

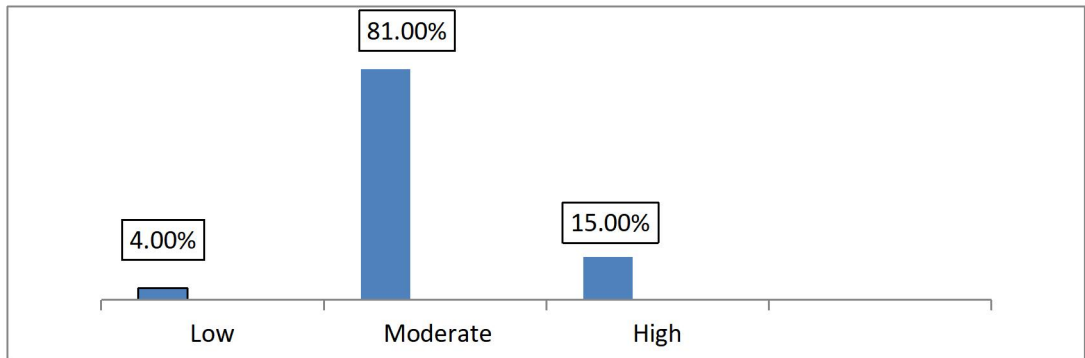
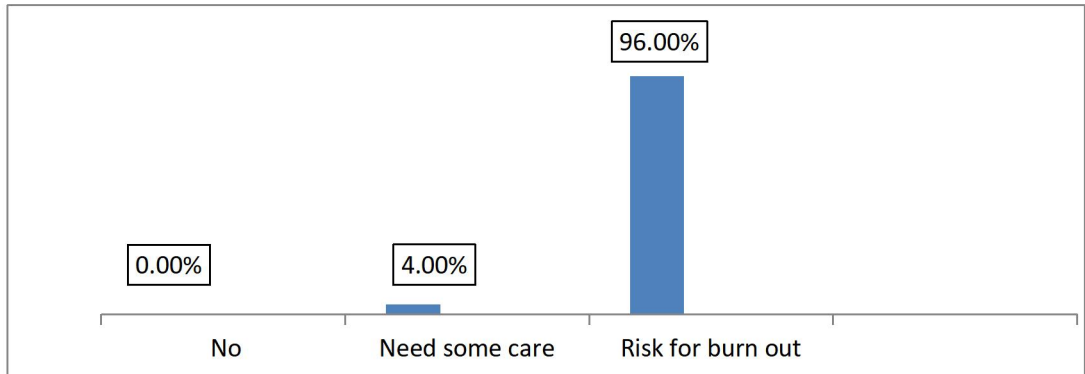


Figure (2): Distribution of the studied caregiver parents according to their overall burden

Figure (3): Distribution of the studied caregiver parents according to their overall self-efficacy

Table (3): Relation between burden, Depression, Self-efficacy and Care giving parents' socio- demographic characteristics

Caregivers data	socio-demographic	Burden (TMs)	Depression (TMs)	Self-efficacy (TMs)
The degree of kinship to the child				
-	Mother	65.27±11.64	39.83 ± 8.0	31.22 ± 7.11
-	Father	49.93±11.18	29.93 ± 9.54	37.60 ±6.81
t (p)		8.413*(<0.001*)	6.839*(<0.001*)	5.729*(<0.001*)
Age				
-	< 25-	69.51 ± 12.43	40.99 ± 9.09	31.47 ± 7.71
-	35-	55.79 ± 10.33	35.38 ± 8.57	33.84 ± 7.13
-	45- 51	55.04 ± 13.44	31.68 ±10.07	34.32 ± 8.32
F (p)		34.120*(<0.001*)	13.671*(<0.001*)	2.592(0.077)
Marital status				
-	Married	60.50 ± 13.44	36.64 ± 9.31	33.06 ± 7.76
-	Widow	65.60 ± 11.61	41.60 ± 11.26	31.80 ± 5.53
-	Divorced	77.0 ± 0.0	46.0 ± 0.0	34.0 ± 0.0
F (p)		2.477(0.087)	2.813 (0.062)	0.209 (0.812)
Educational level				
-	Illiterate	62.03 ± 14.75	33.21 ± 8.76	33.87 ± 7.66
-	Read & write / Primary	57.85 ± 15.09	36.85 ± 9.18	31.65 ± 7.35
-	Secondary school	60.51 ± 15.75	36.83 ± 11.71	33.89 ± 8.52
-	University education	63.03 ± 8.58	39.71 ± 7.69	32.72 ± 6.96
F (p)		1.479(0.222)	4.076*(0.008*)	0.905(0.440)
Occupation				
-	Employee (Private-Governmental)	59.25 ± 10.39	37.45 ± 9.86	33.27 ±7.25
-	Free job (Barber- Chauffeur)	46.43 ± 14.60	27.52 ± 8.50	38.29 ± 9.24
-	House Wife	65.19 ± 12.75	38.76 ± 8.38	31.72 ± 7.01
F (p)		22.148*(<0.001*)	13.876*(<0.001*)	7.094*(0.001*)
Residence				
-	Rural	62.41 ± 14.77	37.52 ± 9.09	31.95 ± 8.47
-	Urban	59.98 ± 12.15	36.78 ± 9.88	33.78 ± 6.72
t (p)		1.246(0.215)	0.549(0.584)	1.651(0.101)
Housing				
-	Living with extended family	61.33 ± 12.75	36.77 ± 6.51	34.30 ± 8.35
-	Living with nuclear family	61.0 ± 13.53	37.16 ± 9.97	32.74 ± 7.43
t (p)		0.125 (0.900)	0.282 (0.779)	1.040 (0.300)
Income				
-	Enough	60.39 ± 13.54	36.95 ± 9.76	32.98 ± 7.69
-	Not enough	66.13 ± 11.05	38.26 ± 7.51	32.96 ± 6.74
t (p)		2.280*(0.030*)	0.618 (0.537)	0.012 (0.990)

F: for ANOVA test t: for t-test *: Statistically significant at $p \leq 0.05$ TMs: Total Means score

Table (4): Relation between burden, Depression, Self-efficacy and parent caregivers' family history and care giving process

Caregivers` data	Burden (TMs)	Depression (TMs)	Self-efficacy (TMs)
Family history with cancer			
- No	60.62 ± 13.38	36.65 ± 9.69	32.93 ± 7.40
- Yes	65.11 ± 13.09	41.42 ± 6.48	33.37 ± 9.30
t(p)	1.392(0.166)	2.094*(0.038*)	0.237(0.813)
Sharing responsibility with caregiver (n=155)			
- The spouse	56.87 ± 14.0	34.96 ± 10.09	35.12 ± 8.07
- Eldest daughter	63.73 ± 16.18	37.30 ± 10.46	32.36 ± 8.77
- Caregivers` father / mother	66.27 ± 7.03	40.18 ± 7.11	32.14 ± 7.91
- Caregivers` brothers / sisters	57.45 ± 11.38	37.15 ± 8.88	30.05 ± 4.49
- Relatives	54.36 ± 11.57	34.55 ± 9.93	28.55 ± 7.69
F (p)	3.506* (0.009*)	1.459 (0.217)	3.089* (0.018*)
Issues bother the caregiver in caring process			
- Side effects of chemotherapy	63.34 ± 12.43	36.94 ± 8.84	32.55 ± 6.08
- Lack of improvement	56.67 ± 9.26	34.36 ± 9.40	32.82 ± 8.14
- Fear of not curing or death	55.78 ± 8.56	39.14 ± 5.76	31.39 ± 7.76
- Child`s behaviour (violence, stubbornness,...)	66.87 ± 16.47	40.60 ± 8.67	27.23 ± 6.25
- Child`s sadness	60.50 ± 10.56	37.75 ± 5.42	36.63 ± 6.23
- Negative impact on caregiver`s time	59.29 ± 13.51	37.32 ± 10.83	33.29 ± 8.28
- The impact on the personal needs of caregiver	63.85 ± 14.58	38.71 ± 11.56	34.65 ± 8.17
F(p)	3.797* (0.001*)	1.589(0.150)	4.105* (0.001*)
Coping with bothering issues			
- Crying and want to be alone	62.59 ± 10.63	39.60 ± 7.69	31.96 ± 7.38
- Read Quran, Praying	61.45 ± 10.96	36.07 ± 7.02	31.60 ± 5.29
- Aggressive behaviours	64.16 ± 16.35	38.86 ± 11.16	34.28 ± 9.47
- Smoking	36.20 ± 6.57	19.80 ± 4.38	40.0 ± 2.74
- Leaving the home	49.39 ± 11.27	29.82 ± 10.18	37.25 ± 5.30
F(p)	12.746* (<0.001*)	12.681* (<0.001*)	2.535* (0.041*)

F: for ANOVA test t: for Student t-test *: Statistically significant at $p \leq 0.05$ TMs. Total Means score

Table (5): Correlation between parent caregivers' overall self-efficacy, overall burden and depression

		Overall burden	Depression
Overall self-efficacy	r	-0.366*	-0.315*
	p	<0.001	<0.001
Overall burden	r		0.759*
	p		<0.001

r: Pearson coefficient *: Statistically significant at $p \leq 0.05$

Discussion

Family caregivers are essential partners in the delivery of complex health care services and this type of caregiver exemplifies the associated caregiver burden and stress during cancer treatment. Family life changes drastically when a child suddenly falls seriously ill and is diagnosed with cancer (Bevans, M., 2012).

Caregiver burden is also dependent upon the age of the caregiver, the present study revealed that there is a significant relationship between caregivers' burden and their age, and it noticed that the younger parent caregivers at age group (<25-) obtained the highest total mean score of burden. This result was supported by Goldstein, N et al. (2004) who studied factors associated with caregiver burden among caregivers of patients with cancer, he reported that younger caregivers experience higher levels

of caregiver burden and report more disruption to their schedules than older adults. **Brink P, (2008)** stated that Family obligations and career interruptions likely impact younger caregivers.

As regards the caregiver's depression, the present study revealed that almost all the studied parent caregivers suffering from depressive symptoms with a high total mean score. This may be attributed to that the diagnosis of cancer has been characterized to result in suffering, pain, social alienation, or may be related to stigma of cancer where there are many misconceptions associated with having cancer such as cancer is a death penalty, these factors may contribute to depression. Early researcher suggested that caregiver depression might result from anticipatory grieving of losses resulting from the patient's illness (**Edwards B 2004**). Parents seem prepared to accept burden of significant symptoms of their children simply because they do not think they should expect anything better (**Waldman E, 2013**) these results are compatible with a German study about cancer caregivers done in 2013 revealed that mild to severe symptoms of depression were found in about two thirds of caregivers. Another study done by **Park B et al. (2013)** revealed that a quarter of the family caregivers of cancer patients reported moderate depression. Korean study revealed that more than two-thirds of caregivers had high depression scores, and about one-third had very high depression scores.

There are several factors that may attribute to caregivers' depression such as lack of improvement of child condition, presence of many side effects of treatment which sometimes the parent caregiver is unable to deal with it. The same result was found by **Erdem, (2008)** who stated that the major responsibility of care giving display symptoms such as hopelessness, anger, stress, anxiety, and depression.

The finding that a large proportion of caregivers suffered from depression suggest that there are unmet needs that are measurable at an early stage of the patient's life-limiting illness, and points to the need for early psychological assessment and potential intervention (**Given B, 2012**) Some studies have investigated the care giving the experience of those caring for cancer patients, and those studies concluded that

caregivers feel overburdened, depressed, anxious, and exhausted (**Cho J, et al 2013**).

Family and social support including assistance with activities of daily living, financial aid and emotional support improves the psychological status of most caregivers, also cancer caregivers who are isolated from extended family members have lacking in family and social support and may have more difficult times (**Gibbins J, 2012**). As well, about one quarter of the studied caregivers in the present study reported that there was no one sharing the responsibilities with them, as they had not any support and take their responsibilities alone without help all the time. **Nijboer et al (2001)** found that social and daily emotional support acted as a moderator of the relation between negative care giving experience and caregiver's depression. **Bayat et al. (2008)** argued this results in a study that examined the impact of childhood cancer on mothers in Turkish culture which revealed that there is a negative relationship was found between social support and depression scores.

Family communication is vital to family functioning, communication reflecting the family relationships and roles and helping it's members stay connected, solving their problems and create new strategies for their life (**Cho J, 2013**). **Waldman E (2013)** reported that parents of those treated for over nine months reporting significantly increased psychological, cognitive, and communication disturbance. In another study of evaluation of the caregivers' burden and quality of life revealed that 6.25% of caregivers presented depression and 9.38% dysphoria. (**Cronin K, 2009**).

The high percent of depression in the studied caregivers in the current study may be related to that more than one third of the studied parent caregivers were highly educated, as the highly educated person are more concerned in reading about the disease, and about its prognosis, side effect and consequences of its treatment. In contrast, **Lit-Zelman K et al. (2011)** found that highly educated caregivers associated with worse QoL because highly educated individuals prefer to be actively involved in the medical decision-making process; in parents of children with cancer, this preference may increase their stress and

negatively influence their QoL. Such parents may also be more likely to seek out information relating to their child's cancer, or be more familiar with the short- and long-term risks that their children face. This could potentially lead to increased fear or worry and worse QoL outcomes (**Perricone G, 2012**).

The present study revealed that caregiver mothers had higher depression scores than fathers. **Edwards B (2010)** who reported that males had lower levels of depression and anxiety than females found the same result. This may be attributed to reporting of some mothers in the present study that when they are anxious or stressed they generally directed their anger toward their partner and this adversely affects interfamilial relations, or they hit their sick child and this may produce guilt feeling resulting in depression. According to a study done by **Duggleby, A, et al. (2014)** to examine the hope of rural women caregivers of persons with advanced cancer, guilt has been found to be an important factor contributing to burden, depression, and distress in family caregivers of cancer survivors. Another cause for this result is the coping ways used by the parent caregivers in this study in which the current study revealed that there is a significant relationship between caregivers' coping ways with bothering issues and their depression, in which using crying and wanting to be alone as a coping way which is used by more than half of the studied caregivers (mainly mothers), obtained the highest total mean score of burden.

On the opposite hand, according to the literature family, caregivers can derive significant benefits from caregiving, reporting a sense of accomplishment in fulfilling the wishes of the patient and a belief that they are able to give something back to the person for whom they are caring. Caregiving also allows family members to spend intimate times together and share moments that are meaningful.

Concerning the caregivers' self-efficacy, the current study has been found that 81.0% of the studied parent caregivers were having a moderate level of self-efficacy. The same result was found by other studies, as **Hampton M (2014)**, **Durmaz H et al. (2014)**, and **Unver V et al. (2016)** who explored caregiving burden and self-efficacy levels of family caregivers

reporting a moderate level of confidence in their ability to manage caregiving demands.

Father caregivers in the current study had higher total mean score of self-efficacy than mothers. This is consistent with the mothers' talk during the interview of the present study, as they reported that fathers seeing themselves able to do anything at any time even if they actually do not give any help and some mothers reported that their husbands deny and ignore the child's illness. On the other hand, some mothers reported that the fathers became more supportive and protective than before. In the same line **Elcigil A et al. (2010)** reported that the mothers interviewed said that they and their husbands experienced a change in attitude and behavior toward their affected child after the diagnosis of the illness; they became more tolerant and protective than before.

The findings of the present study proved significant relation between the studied caregivers' occupation and their self-efficacy, where the housewife caregivers obtained the lowest mean score of self-efficacy. The higher level of self-efficacy related to job possession can be explained by the association between job possession and a higher feeling of usefulness, well-being, and self-esteem which in turn would affect self-efficacy. In addition, a previous study mentioned many benefits associated with working including; income, sense of purpose, social relationships, skill development, and creativity. These benefits are considered to be of particular value to people's self-efficacy and to those with depression. In contrast, **Zakaria M (2008)** reported that the worker patients' self-efficacy were significantly worse than those who were employed.

The present study revealed that there is a significant negative correlation between self-efficacy and parents' caregiver's burden and depression. This is in the same line with the theory which suggests that individuals with higher levels of self-efficacy for performing tasks of caregiving have greater levels of success in completing the tasks, lower levels of psychological and physical illness, reduced rates of burnout, and greater levels of well-being than those with low levels of self-efficacy. At the same line, **Casado B, (2013)** and **Lakhani S (2016)** reported that caregiving self-

efficacy is significantly negatively correlated with the burden of care. Additionally, numerous studies reported that higher self-efficacy will be associated significantly with lower levels of disability, and depression.

The previous findings is consistent with the explanations provided by **Steffen, et al (2002)** as those with a high sense of caregiving efficacy may be protected from the negative consequences of this role by focusing on what they are capable of accomplishing, rather than on their failures. Moreover, it's presumed that self-efficacy would modify the effect of many stressors such as disease severity, the uncertainty of the situation, physical difficulties, psychological state, and family issues and hence on quality of life. This is in accordance with **Peleg et al. (2005)** who found that health stressors had a significant negative effect on the quality of life, and self-efficacy act as a mediator factor between perceived stress and quality of life whereas self-efficacy affects negatively perceived stress. Self-efficacy may reduce and weaken stress to an appreciable degree and lead to decrease the level of burden and improvement in quality of life. On the other hand, **Perez et al. (2011)** argued this result, his study about gender differences in cancer caregiver psychological distress, did not reveal a significant relationship between self-efficacy and burden.

The importance of caregiver self-efficacy was supported by the present study findings. As well, the urgent need for help and to decrease FCs burden and depression as evidenced by the present results. Healthcare providers need to recognize the importance of caregiver self-efficacy. They also need to be aware of the emotional and psychological problems that FCs may battle with, be able to identify those at risk of psychological illnesses, and implement preventive strategies and timely interventions. Moreover, Healthcare providers must identify and support the needs and strength points of caregivers to strengthen their ability to manage the demands of caregiving and should educate and support caregivers in the utilization of effective self-care actions, in order to ease the caregiving process and to decrease its negative consequences on the caregivers especially burden and depression.

Conclusion and recommendation:

Based on the results of the present study, it can be concluded that the great majority of the studied care-giving parents were at high risk for burn out and almost all of them were depressed. They tend to have high scores for both burden and depression. In addition, the majority of them had moderate level of self-efficacy. Caregivers burden significantly positive correlates with depression. As well, the more the self-efficacy they have, the less their burden and depression are.

In the light of the results of the present study, the following recommendations are suggested:-

Recommendation For Nursing

- Continuing assessment of the parents' supportive care needs throughout the cancer journey as individuals experience varying degrees of needs that differ from one another and that may change over time.
- The family caregiver has to be included in the plan of child care, so they should be provided with education to strengthen their ability to manage to live with the cancer patient and reduce the degree of burden.
- Provide family caregivers with a psycho-educational program about how to manage stressful situations and increasing level of self-efficacy.
- Family caregiver needs another potential powerful intervention for support such as Internet support. It helps in meeting the family caregiver's needs for support and information, and to assist family caregiver to manage their own health problems and cope with the burdens of caring for a cancer patient by providing tailored information, as well as a chance for peer and professional communication and support.
- Psychiatric health care nurse have an opportunity to emphasize issue of support family caregiver by collaborating with their colleagues in pediatric oncology, to improve their management of symptoms, including those less visible such as emotional and communication issues.
- More studies are needed to better understand the variations in care giving

experiences over time and how the care giving perspective is influenced by different cultures.

• Further research is required to determine which variables are determinants of psychological adjustment of family caregiver, followed by studies to evaluate the most effective ways of implementing the appropriate interventions.

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