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Caregivers burnout of their children with thalassemia

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***Abstract*---**Background: Thalassemia has a negative influence on emotional and social life of caregivers as it is associated with significant social disruption, emotional or psychological stress and highly involved with children's psychological problems. Aim: The study aimed to assess caregivers` burnout of their children with thalassemia. Design: Descriptive research design was applied in this study. Sample: Purposive sample was equal 116 caregivers. Setting: The outpatient clinics at Mustafa Hassan university hospital for pediatric (Al-fayoum, Egypt). Tools: Two tools were used, first tool: includes structure interviewing questionnaire of demographic characteristics of caregivers and their children, past and present medical history and caregivers` knowledge regarding thalassemia. Second tool: caregivers` burnout tool for thalassemia Result: The study showed that, 60% of studied caregivers had unsatisfactory knowledge regarding thalassemia while, 40% of them had satisfactory knowledge regarding thalassemia. 70% of studied caregivers had high burnout while, 30% of them had low burnout regarding thalassemia. Conclusion: there were significant positive correlation between studied caregivers' total knowledge scores and total burnout scores of their children with thalassemia. Recommendation: implementation of

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health education program for caregivers for management of thalassemia at out-patient clinics.

***Keywords*---**caregiver, burnout, children, thalassemia.

Introduction

Thalassemia defined as a group of inherited hemoglobin disorders resulting from defects in the synthesis of one or more of the hemoglobin chains characterized by microcytic hypochromic anemia. There are two main types of thalassemia, alpha and beta thalassemia. The incidence of thalassemia is high among people living in areas of Mediterranean countries, the Middle East, Africa and Southeast Asia. The major causes of thalassemia include deletions of affected α-globin genes in the affected (chromosome 16) and beta genes in (chromosome 11) [1].

Thalassemia caused by a genetic mutation in the DNA of the cells forming the hemoglobin and this mutation passed genetically from parents to children. Genetic mutations disrupt the production of normal hemoglobin so, low levels of hemoglobin and high red blood cell damage lead to anemia. Genes on (chromosome 16) are responsible for the production of alpha subunits, while genes on (chromosome 11) control the production of beta subunits [2]. Children with thalassemia had poor growth and development, they had poor nutrition, poor weight, severe anemia, bone deformity in the face, fatigue, yellowish discoloration of skin and sclera, skeletal abnormality in legs, growth retardation and abdominal enlargement due to hepato-splenomegaly that affect on emotional, social and self-esteem development of the children negatively [3].

Alpha thalassemia caused by absent or deficient synthesis of alpha-globin chains. Signs and symptoms of α-thalassemia vary according to the number of affected genes in the (chromosome 16). Type 1 of alpha thalassemia called silent carrier state (one gene affected), in which children have no signs or symptoms of thalassemia. Type 2: Called alpha thalassemia trait (two genes affected), in which children had a mild chronic anemia. Type 3: called hemoglobin H disease (three genes affected), in which children had moderate to severe anemia and serious health problems. Type 4: called alpha thalassemia major also called hydrops fetalis, (four genes affected) in which fetus usually die [4].

Beta thalassemia caused by mutations in the hemoglobin beta globin gene. The most severe clinical form beta thalassemia is called transfusion-dependent β-thalassemia in which children require lifelong blood transfusions for survival and prevention of serious complications. β-thalassemia classified into β-thalassemia minor also, called β-thalassemia carrier, β-thalassemia intermedia and β-thalassemia major (also, called Cooley's anemia). Without treatment, children with β-thalassemia major usually die before age 5 years [5]. Treatments for thalassemia often include regular blood transfusions and iron chelation therapy with deferoxamine but the most effective treatment and the only treatment that can cure thalassemia is bone marrow and stem cell transplantation from a compatible related donor. Nutritional supplements are very important of management of thalassemia as folic acid supplements and monitoring of vitamin

(B12) levels because of these Nutritional supplements are key components to making healthy blood cells [6].

The major problems associated with blood transfusions are iron overload or iron deposition and transfusion-transmitted infections (TTIs) including hepatitis C and B virus and antibody formation (alloimmunization). Complications associated with untreated beta-thalassemia leads to splenomegaly, osteoporosis, facial bone deformities due to bone marrow expansion, heart failure due to severe anemia, growth retardation, failure of sexual maturation, failure of endocrine glands resulting in diabetes mellitus and insufficiency of the parathyroid, thyroid, pituitary and adrenal glands resulting in hypothyroidism and hypo-parathyroidism [7].

Caregivers` burnout defined as a state of physical, emotional and mental exhaustion accomplish by change in attitude from positive to negative attitude and indifference. Occur when caregivers don`t get assistance that need or when caregivers feel compelled to do more than are able. Signs and symptoms of caregivers` burnout include fatigue, loss of appetite and headache from over thinking of their thalassemic children` condition. Also, feel anxiety, stress and depression of the future of their children who diagnosed with thalassemia. Caregivers also feel guilty and self-despairing if they spend time on themselves rather than on their thalassemic children [8].

Community health nurse (CHN) plays a critical role in prevention of thalassemia by giving health education to family members about preventive strategies of thalassemia as premarital screening, genetic screening and counseling before marriage. CHN gives health education about causes and risk factor of thalassemia through awareness program and awareness campaigns in health care places as hematology out-patient clinics and maternal and child health centers. Also, CHN gives health education about importance of regular blood transfusion to treat thalassemia and iron chelation therapy to prevent iron overload. In addition, CHN gives advices for importance of follow up to prevent complications which may occur to thalassemic children [9].

Significance of the Study

In Egypt it has been estimated that one thousand children from 1.5 million live births are born each year suffering from thalassemia disease. It is reported that the adult carriers' rate of thalassemia in Egypt is between 9 to 10% of the total population .In Egypt, despite the high prevalence of thalassemia carriers and the growing number of children born each year of thalassemia, there is no national thalassemia prevention program [10].

Thalassemia is very common genetic disorder throughout the world. Almost 70,000 infants are born with beta thalassemia worldwide each year and (3%) of world population are carriers of beta thalassemia while alpha-Thalassemia affects 5% of the world’s population. Consanguineous marriages, a high fertility rate, a high birth rate, a low educational level and early marriages are combined with an unawareness of the thalassemia disease and make developing countries to have a higher number of transfusion-dependent thalassemia children in the world. In general, children with thalassemia major place a considerable burden on their families and health authorities [11].

Thalassemia has various signs and symptoms as general weakness, pallor skin, jaundice, facial and leg bone deformities and abdominal enlargement. Complications that result from iron deposition due to multiple transfusions are ulcerations in legs, various arrhythmias, heart failure, chronic liver failure, slow of child's growth and development according to age, diabetes mellitus, hypothyroidism and hypoparathyroidism and these had impact the general health, psychic health, self-esteem and finally life quality of these children and their families. These families are very much vulnerable to social, psychological and financial problems [12]. Therefore this study was conducted to assess caregivers` burnout of their children with thalassemia.

Aim of the study

This study aims to assess caregivers` burnout of their children with thalassemia through the following objectives

1- Assessing caregivers` knowledge about thalassemia.
2- Assessing caregivers` burnout regarding thalassemia.

Research questions

1- What are caregivers` knowledge about thalassemia?
2- What are caregivers` burnout of their children with thalassemia?
3- Is there relation between caregivers` knowledge, burnout and their demographic characteristics?

Subjects and methods

Research design

A Descriptive research design was used to conduct this study.

Setting

The study conducted in the hematology disorder out-patient clinics in Mustafa Hassan University Hospital for pediatric, Al-fayoum city.

Sampling

A purposive sample was used to achieve the aim of the study. The study sample consists of 116 caregivers who attended the outpatient clinic during 3 months through the period of the beginning of June 2021 until the end of August 2021.The children have been selected according to the following inclusion criteria.

1- Children diagnosed with Thalassemia
2- Age from 3 to 12 years
3- Accepting to participate in the study

Tools for data collection

Two tool of data collection were used to carry out the current study

Tool I: A structured interviewing questionnaire

This tool was developed by researcher after reviewing the national and international related literature and contains three parts:

Part I:(A): Demographic characteristics of the caregivers: this part includes data about caregiver's age, gender, educational level, marital status, occupation, monthly income, place of residence and number family of members.
(B): Demographic characteristics of children: this part includes data about child age, child gender and child order in the family.
(c) Past and present medical history of children and their family: this part includes data about blood relation between mother and father, kinship of relationship, family history of thalassemia and family member who suffer from thalassemia.

Part II: caregivers` knowledge about thalassemia

Caregivers` knowledge about thalassemia, this questionnaire consist of (10) questions including meaning of thalassemia, causes, signs and symptoms, types, diagnostic tests, complications, methods of prevention, methods of treatment, importance of follow up and role of the family in early detection of thalassemia it was designed by researcher in Arabic form to avoid misunderstanding.

Scoring system for knowledge

The answers were formulated as: complete correct answer, incomplete correct answer and don`t know\incorrect answer. Two points for each complete correct answer, one point for each incomplete correct answer and zero point for each don`t know\incorrect answer. The total scores were 20 scores. The total knowledge scores were classified into satisfactory knowledge if percent score was ≥ 50% (10-20 scores) and un-satisfactory knowledge if percent score was ≤50% (<10 scores)

Tool II: Caregivers` burnout tool for thalassemia

This tool was developed by [13] and advanced by researcher which, consists of 4 dimensions

- Emotional Exhaustion which, contains 20 items.
- Social Exhaustion which, contains 18 items.
- Depersonalization which, contains 4 items.
- Involvement which, contains 3 items.

Scoring system for burnout

The response format on the three-point Likert scale ranges from (1= disagree to 3= agree). Three points for each agree answer, two points for each neutral answer and one point for each disagree answer. The total scores were 135 scores for 45 item. High burnout if percent score was ≥60% (81-135 scores). Low burnout if percent score was < 60% (45-<81 scores)

Validity

The developed tool would be formulated and submitted to five experts in community health nursing at Helwan University to review significance of the tools for clarity, relevance, comprehensiveness, understanding and applicability.

Reliability

Reliability of the tools was tested to determine questionnaire items related to each other. Cronbach's Alpha (0.9) for knowledge and (0.86) for burnout tool.

Ethical Consideration

An official permission to conduct the proposed study was obtained from the Scientific Research Ethics Committee. Participation in the study was voluntary and subjects were given complete full information about the study and their role before signing the informed consent. The ethical considerations included explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where was not accessed by any other party without taking permission of the participants. Ethics, values, culture and beliefs was respected.

Operational Item

Preparatory phase

It was included reviewing of past, current, national and international related literature and theoretical knowledge of various aspects of the study using books, articles, internet, periodicals and magazines to develop tools for data collection

Pilot Study

A pilot study was conducted to test the clarity, applicability and understand ability of the tool. It has been conducted on (10%) of the sample equal (11 caregiver) who have children diagnosed with thalassemia and no modification done. The participants of the pilot study were included in the main study sample.

Field work

Before conducting the study, an official letter issued from Dean of Faculty of Nursing, Helwan University and directed to the manager of Mustafa Hassan for pediatric University Hospital in Al- Fayoum city including the aim of the study to obtain permission after establishing a trustful relationship, each subject interviewed individually the by researcher to explain the study purpose. Data was collected within three months of academic year(2020-2021) three days/ week(Sunday, Monday ,Wednesday) from 9 am to 2pm till the needed sample completed, written approval obtained from caregivers after the researcher introduced herself for each caregiver, then explained the purpose of the study to assess knowledge about thalassemia and their burnout. Study collected through structured face to face interview and the entire tool filled by researcher. The researcher utilized two tools that took 20-30 minutes and met the caregivers three days /week. The researcher taken 3-4 caregivers per day, total number of caregiver =116 caregivers.

Administrative Item

An official permission was obtained from the dean of Faculty of Nursing, Helwan University and official permission from director of Al-Fayoum University Hospital to conduct the study, this letter included a permission to collect the necessary and explain the purpose and nature of the study.

Statistical Item

Data collected from the studied sample was revised, coded and entered using Personal Computer (PC). Computerized data entry and statistical analysis were fulfilled using Statistical Package for the Social Science (SPSS) version 24. Data were presented using descriptive statistics in the form of numbers and percentages. Mean ± standard deviation (±SD) to describe results. Appropriate inferential statistics such as T-test was used as well.

Significant of the results

Highly significant at p-value <0, 001
Statistically significant was considered at p-value <0, 05
Not significant at p-value >0, 05

Results

Table (1): Demonstrates that, 53.5% of studied caregiver`s their age between 20 -< 30 years with the mean age were 23.83± 7.34. 89.6 % of them were female. Regarding to caregivers` level of education 36.9 % of them had basic education, while 89.6% of them were married. 81.0% of them were housewife and 51.7% of them had not enough monthly income. Regarding to place of residence, 56.8% of them live in rural area and 43.1% of them had three of family members.
Figure (1): shows that 89.6% of caregivers were female while 10.4% were male.

Figure (2): shows that, 60.0% of studied caregiver`s had unsatisfactory knowledge regarding thalassemia and 40% of them had satisfactory knowledge regarding thalassemia.

Figure 3: shows that, 70.0% of the caregivers had high burnout regarding thalassemia and 30% of them had low burnout regarding thalassemia

Table (2): reveals that, there were statistically significant relation between total scores of caregivers knowledge regarding thalassemia and their age, sex, level of education, marital status of caregivers, occupation, residence, monthly income and numbers of family members (p= <0.001).

Table (3): Shows that, there were statistically significant relation between total scores of caregiver`s burnout and their age, sex, level of education, marital status of caregivers, occupation, residence, monthly income and numbers of family members (p= <0.001).

Table (4): Shows that, there were highly statistically significant positive correlation between total knowledge scores of caregivers and total caregiver`s burnout (p= 0.000**).

Table (1): Number and Percentage Distribution of the Studied Caregivers Related to their Demographic Characteristics (n=116)

Socio-demographic Characteristics of studied caregivers	No.	%
Age		
20- < 30	62	53.5
30- < 40	46	39.6
≥40	8	6.9
Mean ± SD	23.83± 7.34	
Gender		
Male	12	10.4
Female	104	89.6
Level of education		
Can't read and write	38	32.7
Read and write	20	17.3
Basic education	46	36.9
Secondary education	8	6.9
University or more	4	3.5
Marital status		
Married	104	89.6
Divorced	4	3.5
Widow	8	6.9
Occupation		
Employee	4	3.5
Free business	10	8.6
crafts man	8	6.9
Housewife	94	81.0
Monthly income		
Enough and saved	1	0.9
Enough	55	47.4
Not Enough	60	51.7
Place of residence		
Urban	50	43.1

Socio-demographic Characteristics of studied caregivers	No.	%
Rural	66	56.8
Number of Family members		
Three member	24	20.6
Four members	42	36.2
more than 4 members	50	43.1

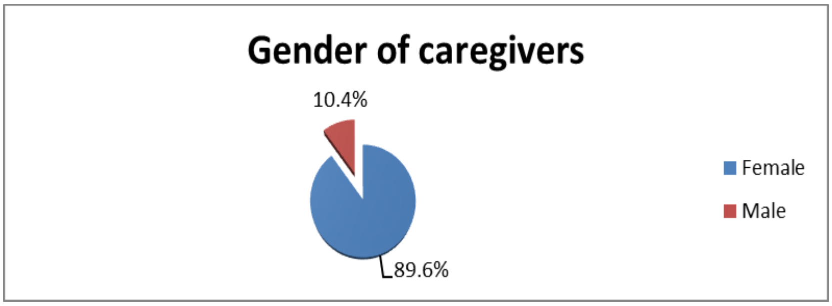

Figure (1): gender of caregivers (n=116)

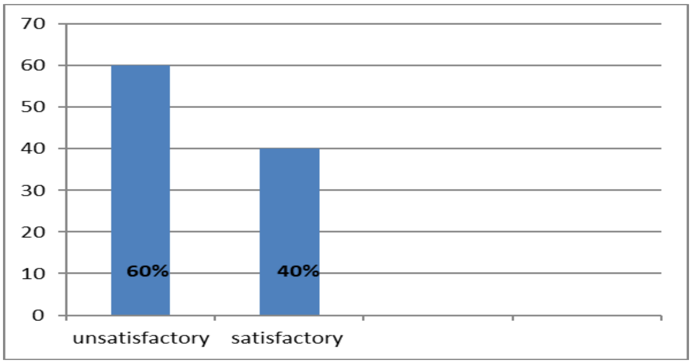

Figure (2): Total knowledge scores of the studied caregivers related to Thalassemia of their children (n=116)

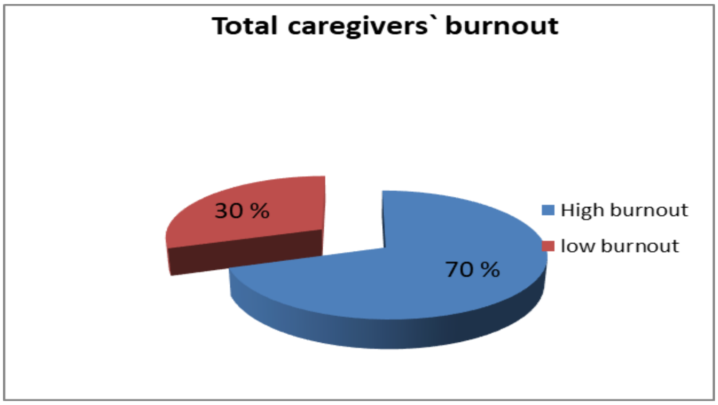

Figure (3): Total caregiver`s burnout regarding thalassemia of their children (n=116)

Table (2): Relation between caregivers` total knowledge and their demographic characteristics (n=116)

Demographic data of caregivers		Total scores knowledge			T-test	P-value
		Mean	±	SD		
Age	20-<30 years	12.833	±	4.665	22.761	<0.001*
	30-<40 years	6.077	±	5.491		
	≥40	4.667	±	6.742		
Sex	Male	9.744	±	8.855	23.782	<0.001*
	Female	5.453	±	7.655		
Level of education	Not read and write	8.823	±	8.579	24.710	<0.001*
	Read and write	5.453	±	7.655		
	Primary school	9.744	±	8.855		
	Secondary school	1.700	±	2.557		
	University or more	10.822	±	4.875		
Marital status	Married	10.834	±	9.667	14.821	<0.001*
	Divorced	12.077	±	8.691		
	Widowed	9.677	±	9.755		
Occupation	Employee	9.823	±	8.544	22.761	<0.001*
	Free business	10.711	±	9.651		
	Handicraft	8.877	±	8.766		
	Housewife	11.611	±	12.641		
Residence	Rural	10.822	±	4.875	21.665	<0.001*
	Urban	8.662	±	7.766		
Monthly income:	Not enough	8.872	±	7.458	20.396	<0.001*
	Enough	6.955	±	6.568		
	enough and saved	17.308	±	6.562		
Number of Family members	Three individual	9.772	±	7.958	21.377	<0.001*
	Four individual	9.472	±	9.558		
	More than four individual	9.662	±	7.987		

(*) statistically significant & (**) high statistically significant P≤0.001

Table (3): Relationship between caregivers` total burnout and their demographic characteristics (n=116)

Demographic data		Total burnout			T-test	P-value
		Mean	±	SD		
Age	20-<30 years	1.333	±	2.066	21.302	0.001*
	30-<40 years	2.231	±	4.475		
	≥40	8.833	±	7.388		
Gender	Male	9.744	±	8.855	23.782	<0.001*
	Female	5.453	±	7.655		
Level of education	Not read and write	8.823	±	8.579	24.710	<0.001*
	Read and write	11.611	±	12.641		

Demographic data		Total burnout			T-test	P-value
		Mean	±	SD		
	Basic education	1.700	±	2.557		
	Secondary education	8.662	±	7.766		
	University or more	10.822	±	4.875		
Marital status	Married	6.955	±	6.568	14.821	<0.001*
	Divorced	12.077	±	8.691		
	Widowed	9.677	±	9.755		
Occupation	Employee	9.823	±	8.544	22.761	<0.001*
	Free business	10.711	±	9.651		
	Handicraft	8.877	±	8.766		
	Housewife	10.711	±	9.651		
Residence	Rural	10.822	±	4.875	21.665	<0.001*
	Urban	8.662	±	7.766		
Monthly income	Not enough	8.872	±	7.458	20.396	<0.001*
	Enough	6.955	±	6.568		
	enough and saved	15.305	±	8.564		
Number of Family members	three members	16.304	±	7.572	20.432	<0.001*
	Four members.	13.212	±	8.542		
	More than four members	19.301	±	9.562		

(*) statistically significant & (**) high statistically significant P≤0.001

Table (4): Correlation between caregivers total knowledge and total burnout regarding thalassemia of their children (n=116)

Variable	Caregivers total burnout	
	R	P value
Caregiver`s Total Knowledge	0.353	0.000**

(*) statistically significant & (**) high statistically significant P≤0.001

Discussion

Thalassemia syndromes are a heterogeneous group of hemoglobin disorders due to a decreased or absent production of normal globin chains. They are the most common recessive diseases worldwide, with an estimation of 1–5% of the global population carriers of a genetic thalassemia mutation. Signs and symptoms of thalassemia include hemolytic anemia, poor growth, yellowish discoloration of the skin and bone deformity in face and legs. Affected children will require regular lifelong blood transfusions and iron chelation therapy. Lack of knowledge and awareness about thalassemia is a major factor which leads families to face serious social, economic and psychological problems [14]. Therefore, this study aimed as to assess caregivers` burnout of their children with thalassemia.

Regarding to age of studied caregivers, the results of the current study demonstrated that, more than half of studied caregivers were ages ranged from 20 - < 30 years with mean ± SD was 23.83 ±7.34. These results agree with study performed by Ibrahim et al [15], whose conduct study in Shebin El-kom city, Menoufia Governorate, Egypt (study sample equal 87 mothers of children with thalassemia) and entitled as "relationship between quality of Life and social support among mothers of children with thalassemia" who stated that, half of studied mothers were ages ranged from (20-35) years with mean ± SD was 24.72 ±8.24. From the researcher point of view, these results might be due to that they married in young age as the marriage age in Egypt is ranged between 20-29years old. Also due to the lack of experience and practice of mothers regard to dealing with thalassemia for their children at this age especially if that is the first child.

Regarding to gender of the studied caregivers, the results of the current study revealed that, majority of studied caregivers were female. These results approved with study performed by Man et al [16], whose conduct study in Peninsular Malaysia (study sample equal 123 caregivers of a children with thalassemia major) and entitled as "Knowledge, attitude and practice towards dietary iron among patients with thalassemia and their caregivers in Peninsular Malaysia", who found that majority of studied caregivers were female. From the researcher point of view, these results might be due to the traditions in Egypt that female caregiver has family and house responsibilities, activity of daily living such as preparing food, shopping and arranging the house, caring of thalassemic child as going to treatment sessions as blood transfusion and iron chelation therapy and caring of other children in the family so that can affect the physical and psychological state of the caregiver and can increase the burnout.

Regarding to educational level of the studied caregivers, the results of the current study revealed that, more than one third of caregivers had basic education. These results agreed with study performed by Biswas et al [17], whose conduct study in India (study sample equal 228 caregivers with children affected by β-TM) and entitled as "Care-Related Quality of Life of Caregivers of Beta-Thalassemia Major Children" who found that, (37.4%) were educated up to primary and preparatory level. From the researcher point of view, these results might be due to the fact that female in Egyptian culture is married younger or may be because there was a common belief in Egypt that the marriage is better than education for girls or due to lower economic status and low educational level of caregivers has some impact on awareness of disease, knowledge about it and prevention of it so, that may lead to increase burnout.

Regarding to marital status of the studied caregivers, the results of the current study revealed that, majority of studied caregivers were married. These results approved with study performed by Khresheh et al [18], whose conduct study in jordan (study sample equal 45 mother of children with thalassemia major) and entitled as "Knowledge and practices among Mothers about Care of their children with Beta Thalassemia Major" who found that 90% of studied caregivers were married. From the researcher point of view, these results might be due to the fact that marriage in Egyptian culture is better for female. Also they consider that marriage to be chastity and protect the woman and the presence of family responsibilities, caring of other children and conflicts or disputes in the family can affect the educational state (no time for reading and gaining information) and psychological state of the caregivers and can increase the burnout.

Regarding to occupation of the studied caregivers, the results of the current study revealed that, more than four fifths of studied caregivers were housewives. These results corresponded with study performed by Mohiuddinet et al [19], whose conduct study in Bangladesh (study sample equal 253 mothers having children with thalassemia.) and entitled as "Parenting Stress of Mothers Having Children with Thalassemia" who found that, 82% of studied mothers were housewives. From the researcher point of view, these results might be due to mother refuse to work outside the home for money but rather devotes all times, energy and love to her thalassemic child and all family and help her to do that the inadequate income from work, as well as lack of occupational chances and unemployment problem in Egypt. Those housewives mothers are not aware of everything new about the disease, how to deal with it, responsibility for her thalassemic child, husband and rest of her children and that increase risk of burnout.

Regarding to the monthly income of studied caregivers, the results of the current study showed that, more than half of studied caregivers had not enough monthly income. These results was in agreement with study performed by Hisam [20], whose conduct study in Rawalpindi Thalassemia Centre, Pakistan (study sample equal 87 caregivers) and entitled as "Perceived stress and monetary burden among thalassemia patients and their caregivers" who found that, 53% of studied caregivers had not enough monthly income. From the researcher point of view, these results might be due to that increase number of family members, majority of caregivers were housewives and increase expenditures on treatment sessions of thalassemic child. Insufficient monthly income makes caregiver borrow money from others to spend on treatment sessions and periodic follow-up for the thalassemic child and may lead to increase in burnout.

Regarding to place of residence of the studied caregivers, the results of the current study showed that, more than half of studied caregivers were lived in rural area. These results matched with study performed by Ahmed et al [21], whose conduct study in Karachi, Pakistan (study sample equal 201parent) and entitled as " Knowledge, attitude and practices (KAP) of The families of B-thalassemia patients in a thalassemia Center of Karachi" who found that, more than half of studied children were living in rural areas. From the researcher point of view, these results might be due to lack of awareness among caregivers regarding thalassemia and limited healthcare facilities to prevent the disease in rural areas.

Regarding to number of family members of the studied caregivers, the results of the current study showed that, less than half of studied caregivers had more than 4 family members. These results matched with study performed by Hussain et al [22], whose conduct study in Pakistan (study sample equal 150 parent) and entitled as "An Analysis of Experiences and Problems of Parents with Thalassemia Children" who found that, less than half of studied families had more than 4 members. From the researcher point of view, these results might be due to Egypt is a developing country or may be in Egyptian customs and traditions, parents prefer many children and consider children their consolation and there is no health education about birth control.

Regarding to total knowledge scores regarding the thalassemia, the results of the current study illustrated that, more than half of the studied caregivers had unsatisfactory total knowledge scores regarding thalassemia. These results matched with study performed by Khalid et al [23], "who mentioned that, more than half of participants had unsatisfactory knowledge regarding thalassemia. From the researcher point of view, these results might be due to lack of community awareness regarding the thalassemia, low educational level of studied caregivers in the present study, which majority of them were primary education and lack of health education in health care centers.

Regarding to total burnout of the studied caregiver, the results of the current study showed that, less than three quarters of studied caregivers had high burnout and less than one third had low burnout. These results agreed with study performed by Prajapati et al [24], who found that, 69% of studied caregivers had high burnout. From the researcher point of view, these results might be due to insufficient social support from relative, neighbors and insufficient financial support from community. Also, might be due to frequent complaints from ttheir thalassemic children and insufficient knowledge about disease.

Regarding to the relation between caregivers` knowledge, burnout and their demographic characteristics of studied, the results of the present study revealed that, there were a statistically significant relation between caregivers` total knowledge scores and their age, gender, level of education, marital status, occupation, place of residence, monthly income and number of family members. These results agreed with study performed by Manzoor & zakar [25], whose conduct study in Lahore (study sample equal 186 parents) and entitled as "Socio-demographic determinants associated with parental knowledge of screening services for thalassemia major in Lahore" who stated that, there were statistically significant relation between parents total knowledge and their gender, level of education, marital status, occupation and monthly income.

Also, these results disagreed with study Performed by Williams [26], whose conduct study at mysore (study sample equal 60 caregivers) and entitled as "A study was to assess the knowledge of caregivers regarding thalassemia in selected hospital at mysore with a view to develop information booklet" who found that, there were no significant relation between total knowledge scores and their age, gender, level of education, marital status, occupation and monthly income. From the researcher point of view, these results might be due to those families who residing in urban areas, families who had sufficient income had better opportunity to acquire more knowledge regarding thalassemia and this could explained that knowledge level was lower among caregivers who residing in rural areas than urban areas. Also, knowledge levels were lower among caregivers who had not enough income, housewives, married and being female less than 30 y.

Regarding to the relation between demographic characteristics of studied caregivers and their total burnout scores, the results of the present study revealed that, there was a statistically significant relation between caregivers' total burnout scores and their age, gender, education, marital status, place of residence, occupation ,monthly income and number of family members. This could be explained as, burnout level was higher among families who residing in rural areas than urban areas, higher among families who had insufficient income, increased according with lower educational level, increased with married caregiver and increased. These results agreed with. Study performed by Abbasi & Manzoor [27], whose conduct study in Pakistan (study sample equal 200 caregivers) and entitled as " Socio-religious prognosticators of psychosocial burden of beta thalassemia major" who stated that, there was significant relation between caregivers' total burnout score and their demographic data as age, gender, marital status, place of residence and income.

Also, these results disagreed with study performed by Prajapati et al [24], who found that, there was no significant relation between age, gender, place or residence, education, occupation and marital status. From the researcher point of view, these results might be due to those families who residing in urban areas, sufficient income , higher education and employed had better opportunity to acquire more knowledge regarding thalassemia, They own recreational places in cities such as clubs and parks, places of health care are close to them, so they do not have to tire or waste time in transportation, they form relationships and friendship with others because of the nature of their jobs and that relieves the degree of burnoutRegarding to Correlation between caregivers` total knowledge and total burnout regarding thalassemia of their children, the results of the current study showed that, there were highly statistically significant positive correlation between total knowledge scores of caregivers and total caregiver`s burnout (p= 0.000**).These results agreed with study performed by Abbasi & Manzoor [27],whose conduct study in Pakistan (study sample equal 197 perants) and entitled as "Socio-religious prognosticators of psychosocial burden of beta thalassemia major" who found that, there were positive correlation between total knowledge scores of caregivers and total caregiver`s burnout. From the researcher point of view, these results might be due the lack of information about thalassemia makes the caregivers do not know how to deal with the children's persistent complaints and can`t able to take right decision about right way of treatment so, that increase their burnout.

Conclusion

On the light of the results of the current study and answers of the research questions, it could be concluded that, there were 60% of studied caregivers had unsatisfactory knowledge and 40 of them had satisfactory knowledge regarding thalassemia. As regarded to caregivers` total r burnout of their children with thalassemia, the current study found that, 70% of studied caregivers had high burnout and 30% of them had low burnout regarding their children with thalassemia. Moreover, there was a statistically significant relation between studied caregivers’ total knowledge and their age, sex, level of education, marital status, occupation, residence, monthly income and number of family members. Also, there is a statistically significant relation between the studied caregiver’s total burnout and their demographic characteristics as age, sex, level of education, marital status, occupation, residence, monthly income and number of family members.

Recommendations

1- Implementation of health education program for caregivers for management of thalassemia at out-patient clinics.
2- Disseminating health education booklets to increase caregiver's awareness regarding thalassemia at outpatient clinics is recommended.
3- Encourage caregivers to seek medical advice for the problems and complications of thalassemia of their children.
4- Further researcher on a large sample size and other setting is recommended.

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