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Assessment of Parents' Psychological Distress and its Coping Strategies Related to Children with Hereditary Blood Disease

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Abstract

Parents receive twice what their child gets if gets sick, so how about if the disease is a genetic blood disease. Parents who have an affected child will suffer as their child suffers, and perhaps more than him, because this disease may lead to the death of their child (1). Objective: the study aim to assess parents' psychological distress and coping strategies related to children with inherited blood disease. Methods: A Descriptive study design to assess the parents' psychological distress and its coping strategies related to children with hereditary blood diseases. Had been applied during the period 28 th February 2022 to 3 th December 2022. Non-probability (purposive) sample of (60) Parents were chosen from the Al-Zahra Teaching Hospital for Maternity and Children's in Thalassemia Center. (22 fathers and 38 mothers). The questionnaire used are the Parental Stress Scale (PSS) to assess the psychological distress and coping strategies were assessed by the brief cope. Results: 96.6% of parents try to be reassured in their religion or spiritual beliefs and always adapt to them. And 92% of parents always pray and hope. 36.7% of parents feel tired without a valid reason during the past thirty days. 40% of parents feel all the time that everything is stressful (effortless). There is a statistical significant relationship between parents' coping strategies with regard to their gender, residency. There is a statistical significant relationship between parents' psychological distresses with regard to their educational level, occupation, monthly income. Conclusion: The majority of parents try to be reassured in their religion or spiritual beliefs and always adapt to them, due to our cultural attribute as Muslim can help individuals intolerance life stress. And most of parents always praying or meditating. Parents always receive emotional support. And most of parents focus their efforts on doing something about the subject they are always.

Keywords
Parents', Distress, Coping, Blood Disease

The parents and the rest of the family are stressed out because of this chronic sickness, Such a circumstance causes a variety of emotional responses and behavioral patterns to exist in the family, which has an impact on how family members interact with one another and their surroundings. Parents are affected by a child's chronic disease on a cognitive, emotional, and daily basis (2). Parents who get the diagnosis frequently experience unfavorable psychological impacts, including post-traumatic stress symptoms. For the majority of parents, psychological discomfort lessens in the months immediately next the

diagnosis, then the drop slows, and three months after the conclusion of treatment, there is only a slight decline (3). Even while the majority of parents are able to overcome the anxiety they felt while their child was ill and receiving therapy, a sizeable subgroup reports needing psychological care after the curative phase of treatment has ended. Only a little amount of study has specifically examined the type of distress experienced by this minority of parents. Given that only a small portion of persons who claim to require psychological assistance after the completion of curative therapy obtain it, and the majority of those who do find it helpful, this indicates a significant vacuum in the literature (4). It is important to create psychological assistance for the public that is acceptable, pertinent, and clinically effective in light of the population's needs and experiences with distress. To gain a deeper knowledge of parental experiences within and outside of the current diagnostic frameworks for psychological distress, further exploratory research is required. This study looked at the psychological anguish felt by parents who fast a need for psychotherapy following therapeutic treatment for their child's blood disease with the overall goal of offering insights regarding how to evolve acceptable, pertinent, and clinically efficient psychological support for parents of children treated for blood diseases (5). Objectives of the current Study: to assess parents' psychological distress and coping strategies related to children with inherited blood disease. To find out the relationship between the parents' psychological distress and coping strategies with their socio-demographic variables and their knowledge.

Material/Subjects/Patients and methods

Design of the Study

A descriptive study design to assess the parents' psychological distress and Its coping strategies related to children with hereditary blood diseases (thalassemia, sickle cell anemia and hemophilia). Had been applied during the period 28 th February 2022 to 3 th December 2022.

Setting of the study

The study was conducted at the thalassemia unit within al-zahra teaching hospital for maternal and child in al-najaf city in order to obtain accurate and thorough data. Children with inherited blood diseases can receive free medical care from this center.

Sample of the study

Samples collected from the thalassemia center at Al-zahra Teaching Hospital for Maternity and Children, a non-probability (purposive) sample of (60) parents was chosen. (22 fathers and 38 mothers).

Criteria for Selection of the Sample

1. Parents who were agreed and willing to participate in the study.
2. All educational levels of parents
3. Fathers and mothers of children with hereditary blood disease.

The Instrument

Through review of the related literature and studies, the questionnaire used are the Parental Stress Scale (PSS) to assess the psychological distress. This scale has five answers, which are (not any time), (a little time), (some of the time), (most of the time), (all of the time) to choose the answer that expresses true feelings (6). Coping strategies were assessed by the Brief COPE, There are lots of ways to try and deal with stress. This questionnaire asks YOU to indicate what you generally do and feel when YOU experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress. (7).

Validity of the Questionnaire

The validity of an instrument contents is its ability to collect the data prepared to be gathered (8). The content validity of the initial produced instrument is determined by an expert panel that looks into the questionnaire's clarity, relevancy, and suitability in measuring the notion of interest. The questionnaire design is a preliminary version that was submitted to (9) specialists.

Reliability of the Questionnaire

The degree to which a questionnaire reports the same results over time is referred to as

reliability. In a nutshell, it refers to constant scores or raters across time (10). The reliability of the instrument was established using the Pearson Correlation Coefficient, and dependability was assessed using the test-retest method. The Pearson Correlation Coefficient was utilized to assess the reliability of the current study instrument using the Statistical Package for Social Science Program (IBM SPSS) version 26.0. The survey was statistically reliable, meaning it had an adequate level of internal consistency and comparable measurability.

Data Collection

Before embarking on the process of data collection, the researcher has made the arrangements required for obtaining the study samples in the Thalassemia Center of the Al-Zahra Teaching Hospital for Children and Maternity in Al-Najaf City. The data were collected during the period from 7 th August 2022 to 29 th of September 2022.

Statistical data analysis approaches

Statistical Tests That Are Descriptive

The frequency (F): The frequency of an incidence in statistics is indeed the number of times it occurs in a study or experiment. (11)
Percent (%): A figure or rate represented as a particular number of parts of something divided into 100 parts is called a percentage (12).
M.S. (Mean of Score): The mathematical mean is the total of a data set's values of individual divided by the total number of values (13).
SD (standard deviation): a set of data values is a statistic that is used to assess the amount of variation or dispersion in the data. (14)

Inferential Statistical Tests

The Cronbach's alpha: a test reliability estimate that measures the test score's internal consistency and stability or inter-item homogeneity. (15). It was used for determine the reliability of knowledge scale.
(ANOVA): are used to compare (test) the statistical significance of three or more means (groups or variables). They are a set of statistical models that are used to investigate the differences in group means and processes (such as "variation" among and across groups). It's comparable to multiple two-sample t-tests in theory, but it's much more conservative (resulting in less form I error) and so better suited to a wide range of applications. (16). It was used for determine the significant differences in parents' knowledge with their socio-demographic characteristics.
T (independent t-test): The independent-samples t-test, also known as the student's t-test, appears to be an inferential statistical criterion for assessing if the means of two unrelated groups differ statistically signficantly. (17). It was used to determine the significant differences in parents' knowledge with regard to their demographic characteristics.

Results

In order to analyze the findings of the current study, statistical techniques were used; the findings were then organized and analyzed. Those conclusions are based on sample responses to the research instrument.
Table No (1). 96.6% of parents try to be reassured in their religion or spiritual beliefs and always adapt to them. And 92% of parents always pray and hope. Parents always receive emotional support by 55%. And 78% of parents focus their efforts on doing something about the subject they are always in, while adapting to it sometimes by 15%. The percentage of pivot points for adaptation to the above table was 44.1% always, 31.1% sometimes, and 24.8% never.
Table No. (2) Shows the psychological distress of the parents and during the past thirty days, how long did the parents feel tired without a valid reason? The percentage was 36.7% all the time and 31% most of the time. During the past thirty days, 40% of parents feel all the time that everything is stressful (effortless), and 15% of them feel most of the time, And the state of depression of the parents during the past 30 days all the time constitutes 40% . The percentage of psychological distress through the table and according to the total points of the axis was 21.3%, none of the time. 22.7% A little of the time, 23.0 some of the

time, 15.5 most of the time, and 17.5 all the time.

Table 1: The Brief Cope Scale

Coping dimensions		I usually do this		Some time		I usually do not do this at all	
		n.	%	n.	%	n.	%
1-	I've been concentrating my efforts on doing something about the situation I'm in.	47	78.3	9	15.0	4	6.7
2-	I've been taking action to try to make the situation better.	47	78.3	13	21.7	0	0
3-	I've been trying to come up with a strategy about what to do.	35	58.3	23	38.3	2	3.4
4-	I've been thinking hard about what steps to take.	39	65	20	33.3	1	1.7
5-	I've been trying to see it in different light, to make it seem more positive.	45	75	14	23.3	1	1.7
6-	I've been looking for something good in what is happening.	38	63.3	19	31.7	3	5.0
7-	I've been accepting the reality of the fact that it has happened.	37	61.3	19	31.7	4	6.7
8-	I've been learning to live with it.	39	65	18	30.0	3	5.0
9-	I've been making jokes about it.	29	48.3	16	26.7	15	25.0
10-	I've been making fun of the situation.	9	15.0	5	8.3	46	76.7
11-	I've been trying to find comfort in my religion or spiritual beliefs.	58	96.6	1	1.7	1	1.7
12-	I've been praying or meditating.	55	91.7	5	8.3	0	0
13-	I've been getting emotional support from others.	33	55.0	21	35.0	6	10.0
14-	I've been getting comfort and understanding from someone.	26	43.3	29	48.3	5	8.4
15-	I've been trying to get advice from other people.	26	43.3	32	53.3	2	3.4
16-	I've been getting help and advice from other people.	22	36.7	32	53.3	6	10.0
17-	I've been turning to work or other activities to take my mind off things.	21	35.0	27	45.0	12	20.0
18-	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, or shopping.	15	25.0	25	41.7	20	33.3
19-	I've been saying to myself "this isn't real.	12	20.0	29	48.3	19	31.7
20-	I've been refusing to believe that it has happened.	11	18.3	31	51.7	18	30.0
21-	I've been saying things to let my unpleasant feelings escape.	15	25.0	38	63.3	7	11.7
22-	I've been expressing my negative feelings.	11	18.3	30	58.0	19	31.7
23-	I've been using alcohol or other drugs to make myself feel better.	9	15.0	10	16.7	41	68.3
24-	I've been using alcohol or other drugs to help me get through it.	13	21.7	4	6.7	43	71.6
25-	I've been giving up trying to deal with it.	10	16.7	8	13.3	42	70.0
26-	I've been giving up the attempt to cope.	11	18.3	13	21.7	36	60.0
27-	I've been criticizing myself.	13	21.7	14	23.3	33	55.0
28-	I've been blaming myself for things that happened.	14	23.3	17	28.3	28	46.6
	Total	740	44.1	522	31.1	417	24.8
N= Number, %: Percentage							

Table 2: Parental Distress Scale

questions		None of the time		A little of the time		Some of the time		Most of the time		All of the time	
		n	%	n	%	n	%	n	%	n	%
1	In the past 4 weeks, about how often did you feel tired out for no good reason?	5	8.3	4	6.7	10	16.7	19	31.7	22	36.7
2	In the past 4 weeks, about how often did you feel nervous?	8	13.3	13	21.7	18	30.0	11	18.3	10	16.7
3	In the past 4 weeks, about how often did you feel so nervous that nothing could calm you down?	12	20.0	18	30.0	19	31.7	7	11.7	4	6.7
4	In the past 4 weeks, about how often did you feel hopeless?	28	46.7	16	26.7	9	15.0	4	6.7	3	5.0
5	In the past 4 weeks, about how often did you feel restless or fidgety?	8	13.3	20	33.3	11	18.3	12	20.0	9	15.0
6	In the past 4 weeks, about how often did you feel so restless you could not sit still?	8	13.3	19	31.7	15	25.3	9	15.0	9	15.0
7	In the past 4 weeks, about how often did you feel depressed?	13	21.7	11	18.3	16	26.7	8	13.3	12	20.0
8	In the past 4 weeks, about how often did you feel that everything was an effort?	3	5.0	4	6.7	20	33.3	9	15.0	24	40.0
9	In the past 4 weeks, about how often did you feel so sad that nothing could cheer you up?	10	16.7	18	30.0	13	21.3	10	16.7	9	15.0
10	In the past 4 weeks, about how often did you feel worthless?	39	65.0	7	11.7	7	11.7	4	6.7	3	5.0
	total	134	21.3	130	22.7	138	23.0	93	15.5	105	17.5
N= Number, %: Percentage											

Table No. (3) shows there is a significant relationship between gender and coping strategies, whereas the number of father increases the coping related to hereditary blood disease increases, and it also shows that there is a significant relationship between resident and coping strategies of parents, while the population of the city increases, the coping strategies increase, and this is explained by (T) value and the (p-value ≤ 0.05).

Table 3: Shows the relationship between parent's sociodemographic characteristics (gender and resident) and coping strategies related to children with hereditary blood disease.

Characteristics of parents		N	Mean	)S.D(	Std. Error Mean	T-test	P-value
Gender	father	22	1.808442	0.1907562	0.0406694	2.14	0.047
	mother	38	1.509211	0.2211382	0.0358734		
Residency	Urban	36	1.8	0.2191671	0.037046	2.375	0.041
	Rural	24	1.321	0.2034603	0.0424244		
P-value: probability value, N= Number, S.D: Standard Deviation							

Table No. (4) shows the relationship between and sociodemographic characteristics and coping strategies of parents related to children with hereditary blood disease, where there exploring a significant relationship between educational level and coping strategies, as well as there is a relationship between occupation and coping strategies, and also the number of children has a significant role in relation to coping strategies and income Monthly has a significant role in coping strategies, as shown by the value of (F) and (p-value ≤ 0.05)

Table 4: Relationship between parent's sociodemographic variables and coping strategies related to children with inherited blood disease.

Characteristics of parents	Sources	Sum of Squares	df	Mean Square	F	P-value
Level of education	Between Groups	0.255	5	0.051	2.188	0.027
	Within Groups	2.319	54	0.043		
	Total	2.574	59			
Occupation	Between Groups	0.166	3	0.055	2.288	0.024
	Within Groups	2.407	56	0.043		
	Total	2.574	59			
Number of children in family	Between Groups	0.122	3	0.041	1.931	0.032
	Within Groups	2.451	56	0.044		
	Total	2.574	59			
Monthly income	Between Groups	0.125	2	0.062	2.455	0.022
	Within Groups	2.449	57	0.043		
	Total	2.574	59			
df: Degree of freedom, F: F-Statistic, P-value: Probability value						

Table No. (5) The study result display that there is a significant relationship between gender and psychological distress, as the number of father increases, so does their psychological distress. It also shows that there is a high significant relationship between resident and psychological distress, as the more rural population increases also the psychological distress increases, and this is explained by the value of (T) and (p-value ≤ 0.05).

Table 5: Relationship between socio-demographics (gender and resident) and psychological distress among parents:

Characteristics of parents		N	Mean	Std. Deviation	Std. Error Mean	T-test	P-value
Gender	Father	22	2.886364	0.7796797	0.1662283	1.732	0.049
	Mother	38	2.015789	0.8022018	0.1301343		
residency	Urban	36	2.62	0.6008817	0.1015675	2.939-	0.003
	Rural	24	3.086957	0.9221045	0.1922721		
N= Number, P-value: Probability value							

Table No. (6) The study result display relationship between sociodemographic Characteristics and psychological distress of parents related to children with inherited blood disease, there was a significant relationship between the educational level and psychological distress, as well as a relationship between occupation and psychological distress, and also

the monthly income has a significant role in psychological distress, as shown by Through the value of (F) and (p-value ≤ 0.05), while there is no relationship between the number of children in the family and psychological stress because the P-value is more than 0.05.

Table 6: The relationship between socio-demographics (educational level, occupation, number of children per family, and monthly income) and psychological distress among parents:

Characteristics of parents	Sources	Sum of Squares	df	Mean Square	F	P-value
Level of education	Between Groups	3.244	5	0.649	2.049	0.039
	Within Groups	33.402	54	0.619		
	Total	36.646	59			
Occupation	Between Groups	1.672	3	0.557	1.892	0.041
	Within Groups	34.974	56	0.625		
	Total	36.646	59			
Number of children in family	Between Groups	0.195	3	0.065	0.1	0.96
	Within Groups	36.451	56	0.651		
	Total	36.646	59			
Monthly income	Between Groups	2.067	2	1.034	2.704	0.009
	Within Groups	34.579	57	0.607		
	Total	36.646	59			
df: Degree of freedom, F: F-Statistic, P-value: Probability value						

Discussion

The most of participants in the study were mothers and reassured in their religion or spiritual beliefs and always adapt to them, the study finding agree with a study done by Hossain, et al. who conducted a research study on the anxiety and stress that mothers of children with developmental impairments experience. These mothers could turn to devout and spirituality as coping techniques to assist them in adjusting to life changes as well as in finding solutions to issues (18). Four major subject emerged from the study's findings: "The journey to acceptance," "The meaning/purpose of life," "Concerns about the future," and "Coping methods." According to the study's findings, Najaf City parents of children with inherited blood diseases frequently turn to their religious or spiritual convictions as a coping mechanism. They were able to deal with the pressure of their new life by turning to their spirituality. Their feelings of love and commitment for their children increased as they started to perceive them as the ones who gave their lives meaning and purpose. The parents were most concerned about the fate of their children after the parents had passed away. The psychological distress of the parents and during the past thirty days, the parents feel tired without a valid reason was 36.7% all the time and 31% most of the time. The findings of the study agree with Abdul Ameer, et al. revealed that caregivers of children with D.S. have severe level of psychological distress (38.7%) (19). There is a relationship between parents' psychological distress and its coping strategies related to children with hereditary blood disease and their socio-demographic characteristics, the study findings agree with the study done by Ayodeji A Bioku, et al that reviled the participants was significantly related with emotional distress. Likewise, caregivers whose children join hospitals more often are more likely to report emotional distress. (20) The study findings disagree with the study done by Azizah Othman et al. The majority of the individuals said they felt psychologically good, which reviled them. None of them reported any substantial stress, and sixty-three (92.6%) of them reported no depression or stress. Stress symptoms averaged 4.25 (SD = 3.26) and anxiety symptoms 3.54 (SD = 3.54), respectively. A tiny percentage of parents of children with thalassemia whose treatment involved blood transfusions reported experiencing psychological anguish. However, the majority of the caregivers reported being psychologically stable and had used faith, acceptance, and positive reframing as coping mechanisms to manage the psychological anguish while caring for the TDT children. (21).

Conclusion

The majority of parents try to be reassured in their religion or spiritual beliefs and always adapt to them. And most of parents always praying or meditating. Parents always receive emotional support. And most of parents focus their efforts on doing something about the subject they are

always.The psychological distress of the parents during the past thirty days, how long did the parents feel tired without a valid reason, the most of parents were all the time and most of the time. The parents feel all the time that everything is stressful (effortless).

In terms of their gender and place of residence, parents' coping mechanisms have a statistically significant association. Parents' coping mechanisms are statistically significantly correlated with their degree of education, employment, monthly income, and the number of children they are raising. There is a statistically significant correlation between parents' psychological discomfort, their gender and place of residence. Parents' psychological anguish and their degree of education, employment, and monthly income are statistically significantly correlated, to their educational level, occupation, monthly income.

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