

Investigating the mental health and coping strategies of parents with major thalassemic children in Bandar Abbas

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ABSTRACT

Introduction: Major thalassemia is a hereditary, chronic blood disease caused by the synthesis deficiency of one or more polypeptide chains of globin during childhood. This leads to the rise of blood pressure and family tensions. Therefore, the coping strategies of the family could seriously affect and facilitate the thalassemic child's healthy growth. The present research sought to investigate the mental health and coping strategies of families with major thalassemic children in Bandar Abbas in 2013. **Materials and Methods:** This study is of a descriptive-analytical and cross-sectional type. Research population consisted of 140 parents of major thalassemic children who visited Shahid Mohammadi Hospital of Bandar Abbas. The instruments used were the 12-item General Health Questionnaire of Goldberg and Williams along with the coping strategies questionnaire. Nonprobabilistic, convenient sampling method was used. To analyze the data, Spearman's correlation coefficient, Chi-square and descriptive statistical tests were used. The significance level was set at $P < 0.05$. **Results:** Data analysis showed that parents' mental health (32 ± 4.25) along with their coping strategy scores (45 ± 7.50) was about the average. The most prevalent coping strategies among the parents were represented as: "I trust in God in order to get my problems solved" (87%), "to get mentally and spiritually relieved, I would visit mosques and holy shrines" (53%), and "to overcome problems, I make harder attempts" (50.7%). A significant correlation was found between the parents' coping strategies and general health ($P < 0.001$). A significant correlation was also observed between mother's educational level ($P = 0.044$), age ($P = 0.022$) and general health. **Discussion and Conclusion:** According to the results of this research, it is categorical for the ministry of health and medical education and those in charge to pay special and adequate attention to the social, spiritual, and mental health of these children and their families.

Key words: Children, mental health, parents' coping strategies, thalassemia

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INTRODUCTION

Major thalassemia is a hereditary, chronic blood disease caused by the synthesis deficiency of one or more polypeptide chains of globin. Based on Mendel's genetic laws, it is passed down from one generation to the next. Among the symptoms are: Chronic and severe anemia, deficient growth, enlarged spleen and liver, skeletal disorders, especially in the head and face bones along with a change of normal appearance.^[1] The Global Health Organization has introduced thalassemia as the most prevalent genetic disease in 60 countries which, to a great extent, affects the life of about 100,000 infants. In our

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country, it is also the most prevalent genetic disease. National statistics report the existence of 22,000 major thalassemic patients in the country.^[2] Besides the pain and other physical side-effects of thalassemia, thalassemic children suffer from recurrent absence from school, low academic achievement, lack of self-confidence, lack of independence, limitations of social communication, concerns about early death and thinking about the divergence of their life from a normal one. These lead to depression and aloofness and also negatively affect the patient's and their families' spirits.^[3] Alavi *et al.*'s investigation of the life quality of thalassemic children and their families revealed that parents are more concerned about the emotional aspects than the children themselves. Due to the tragic physical state of their children, what they suffer more from is their emotional health. It indicates that having a sick child is a source of stress in their lives.^[4] Since the majority of thalassemic patients are among the child and teenager population of our country, the family's role in their treatment is highly crucial.^[5] Parents as the core of the family are responsible for satisfying the child's daily needs. Therefore, under the effect of the above-mentioned factors they experience higher mental pressure and tension.^[6] The family's efficient coping with this condition can facilitate the healthy growth of the child afflicted with a chronic disease.^[7] With regards to recent medical advancements and the decrease of thalassemia-induced morbidity, the life quality of these patients has become a significant index of medical healthcare.^[8] What seems to be essential is to devise medical and social policies for the prevention, diagnosis and early solution of the different problems these patients are faced with in life. Without taking into account their mental health, it is not possible to provide peace and quiet for these children and their families.^[9] In Pakbaz *et al.*'s study, the most deficient aspect of thalassemic patients' lives was their emotions including anxiety, depression and concerns about their health condition. Affliction of one member of the family led to a kind of psychological crisis for the whole family.^[10] In Meaman's study on how parents of mentally retarded children resisted against stressors, 88.8% of mothers and 85.2% of fathers were found to be worried about their children's prospective life.^[11] In another study conducted by Lopez *et al.* the coping strategies of families were investigated who had children with or without delayed motor development. The former were found to experience higher levels of stress.^[12] Koizumi investigated Japanese mothers' reaction to their child's diagnosis of diabetes. Upon hearing the news, they showed signs of shock, aloofness, depression, high levels of anxiety, loss of weight and exhaustion. In a year's time, they started coping with this condition. Parts of these findings were divergent from those carried out among American mothers. This could be due to the different cultures.^[13] Nemat and Shahabzian conducted a research on the correlation of diabetes-induced stress among mothers and their general health. Only 24% of them were found to be generally healthy. Among the main sources of stress mentioned by these mothers were: Probability of child's hospitalization, physical problems, marriage and birth-giving.^[14] In another study, Akbarbegloo and Habibpour investigated that the correlation

of mental health and coping strategies among parents of thalassemic children. Their findings revealed that the most prevalent coping strategy was "trust in God" and "attempts at overcoming the problems."^[9] Hashemi *et al.* studied 72 Shirazi participant parents whose children had cancer. Moral support was found to be the highest and social support the lowest level of coping strategy.^[15]

Hormozgan having 1455 major thalassemic patients^[16] ranks second in Iran. Devising medical and social policies is essential in order to organize the prevention, diagnosis and solution of the existing problems in these patients' life. Without taking into account all aspects of the disease it is not possible to provide these children and their families with a peaceful life. Provision of these patients and their families' mental health could lead to understanding their specialized needs and using effective healthcare and medical plans. Little research with this concern has been conducted in Iran. No such research has been done in Bandar Abbas to investigate the mental health and coping strategies of these patients and their families. We found it essential to carry out a research with this aim in Bandar Abbas in 2013. Consequently, the appropriate planning can be done with the aim of promoting the mental state of these patients and their families in all aspects.

MATERIALS AND METHODS

The present research is of a descriptive/analytical, cross-sectional type. The target population is comprised of all children afflicted with major thalassemia living in Bandar Abbas (400 people). The sample was selected according to the inclusion criteria, review of previous research, and patients' consent.^[14,15,17] They were 140 patients selected through nonprobabilistic, convenient sampling method. Inclusion criteria: Total consent, patient's age <18, not having a child afflicted with an incurable disease, no recent stress due to death, divorce, etc., exclusion criteria: Refusal to participate, current mental disorder, and a disabling chronic disease. The data collection instruments were two questionnaires. The first one was comprised of two sections the first of which included the items related to parents' and children's demographic information. Such information included age, gender, educational level, occupation, child's disease, presence of another sick child and his/her type of disease. The second part of the questionnaire contained 12 general health questions devised by Goldberg and Williams in 1988. It aimed to measure one's current state of mental health. It focused on two domains of ability: Performing ordinary activities and undesirable experiences.^[18] General Health Questionnaire (GHQ) is also available in versions 60, 20, 28, and 30. The 12-item version is as effective as the 30-item questionnaire. It investigates a particular symptom or recent behavior in an individual. Scoring was in the Likert type (0-1-2-3), and between 0 and 36. Based on the score obtained from this questionnaire, the parents' overall quality-of-life and general health was measured. Individuals who enjoyed a higher quality-of-life and better general health obtained a lower score from GHQ. On the other hand, those

who had a life quality of “very bad” to “bad” obtained a significantly higher score from GHQ-12. The instrument’s content was validated and its reliability was estimated through Cronbach alpha, which was equal to 0.86.^[19] The second part of the questionnaire was devised by Ghazanfari *et al.* It consisted of 20-items of coping strategies in the scales of “always,” “occasionally” and “never.” The reliability of this questionnaire was determined to be 0.79.^[20] The scoring system was of a Likert type (0-1-2) and between 0 and 40. A higher score was indicative of a higher coping ability. To confirm its reliability, the questionnaire was given to 20 subjects in a pretest and posttest. Using Cronbach alpha, the reliability of this instrument was found to be 0.65, and between 0 and 40. A higher score was indicative of a higher coping ability. The data were collected after obtaining permission and an introductory letter from the University’s Vice-President of Research. The purpose of research and instructions on how to fill out the questionnaire were provided for the parents. They were selected among those visiting the thalassemia section of the hospital for their children’s blood injection. The items were read out for those parents who were illiterate and their responses were collected orally. Having been collected, the data were analyzed by SPSS 19. Descriptive statistical procedures were used to determine the frequency and percentage. Spearman correlation coefficient, regression, and Chi-square were used to find the correlations of the variables. The significance level was set at $P < 0.05$.

RESULTS

There were a total of 140 parents. From each couple, one parent was studied. To make sure of homogeneity, an equal number of fathers and mothers were initially selected. However, due to the refusal of most of the fathers, finally 77 mothers (55%) and 63 fathers (45% entered this research). The parents were in the age range of 20–74. Their average age was 41 ± 11.87 . 87 of the thalassemic children were girls and 53 were boys. Children were in the age range of 6–18. 46 of them were younger than 10 and 94 were above 10 years of age. From among the 140 parents, 20 were illiterate, and the rest were literate. Totally 17 of the fathers were unemployed and 123 had jobs. Concerning mothers’ jobs, 20 of them were employed and the rest were housewives [Table 1].

The research findings showed a significant correlation between parents’ education ($P = 0.044$), parents’ age ($P = 0.021$), mother’s age ($P = 0.022$), coping strategies ($P < 0.001$) and parents’ general health. The risk value of inefficient coping strategies and mental health were odds ratio (OR) = 5.65,

95% confidence interval ($CI_{95\%}$) = 2.43–13.1. The risk of a mother younger than 40 years of age and mental health was $OR = 2.32$, $CI_{95\%} = 1.126$ –4.791. The risk of parents’ illiteracy was $OR = 0.274$, $CI_{95\%} = 0.076$ –0.987 while that of mother’s job was $OR = 3.23$, $CI_{95\%} = 1.2$ –8.57 [Table 2].

The mean score of parents’ mental health was 32 ± 4.25 . The mean score of coping strategies was 45 ± 7.50 .

According to the findings, the most prevalent coping strategies among parents were “I trust in God to solve my problems” (87%), “I visit mosques and holy shrines for spiritual relief” (53%), and “I make harder attempts to overcome my problems” (50.7%).

Moreover, a significant correlation was found between parents’ coping strategies and general health ($P < 0.001$) [Table 3].

Regression test helped to examine the effect of the intervening factors. Variables such as one’s coping strategies (e.g., praying, visiting holy shrines, etc.), mother’s job and parents’ age were identified as effective variables on general health [Table 4].

DISCUSSION

The present research sought to investigate the correlation of mental health and coping strategies of parents with thalassemic children in Bandar Abbas. As mentioned in the results section, a positive correlation was found between mental health and coping strategies of the participants. The birth

Table 1: The distribution of frequencies of the research variables

Variable	Groups	Frequency	Percentage
Parent’s age	<40 years	77	55
	≥40	63	45
Parent’s gender	Female	77	55
	Male	63	45
Child’s age	<10 years	46	32.9
	≥10	94	67.1
Child’s gender	Female	87	62.1
	Male	53	37.9
Father’s job	Unemployed	17	12.1
	Employed	123	87.9
Parent’s education	Illiterate	20	14.3
	Literate	120	85.7
Mother’s job	Housewife	120	85.7
	Employed	20	14.3

Table 2: Correlation of demographic variables of parents with thalassemic children and coping strategies

Variable	Groups	Mental health (%)		Frequency	OR	P
		Undesirable condition	Desirable condition			
Education	Illiterate	3 (15)	17 (85)	20	0.274	0.044
Age	Below 40	34 (44.2)	43 (55.8)	77	2.32	0.021
Mother’s job	Employed	12 (60)	8 (40)	20	3.23	0.022
Coping strategy	Low	22 (66.7)	11 (33.3)	33	5.65	<0.001

OR=Odds ratio

Table 3: Correlation coefficient of general health and parent's coping strategies

Variable	Mean±SD	Spearman coefficient	P
Coping strategies	45±7.50	1.000	<0.001
General health	32±4.25	0.037	

SD=Standard deviation

Table 4: The estimated coefficients for the final logistic regression

Variable	B	SD	df	OR	CI 95%		P
					Low	High	
Coping strategy	1.611	0.450	1	5.010	2.075	12.095	0.000
Mother's job	1.112	0.537	1	3.039	1.060	8.711	0.039
Education	-0.818	0.682	1	0.441	0.116	1.681	0.230
Age	1.011	0.584	1	2.079	1.043	5.037	0.049
Constant	-1.992	2.499	1	0.136	-	-	0.425

SD=Standard deviation, CI=Confidence interval, OR=Odds ratio

of a sick child in a family as a crisis could deeply influence the relationships and acts of the family. Only those who have open, constant and effective relationships and are flexible in their roles can readily cope with the crisis. It could be said, on the other hand, that the presence of a sick member limits the whole family's social relationships. More severe the disease is, the more limited the spare time and social communications of the family.^[21] According to Bowen, once the family members become unable to distinguish themselves adequately from the source family, different forms of disorders arise in the family's performance. What is meant by self-distinguishing is the ability of controlling one's emotions while being a member of a passionate family. In Bowen's view, only then a kind of fusion is formed in which one's realistic perspective is overshadowed by stimulation. The product of this fusion would be an intermingled emotional unity. The more the family feel in danger, the closer they tend to get together.^[22] In other words, the more distinguished the parents are and the more emotionally independent they tend to be, the more helpful they would be under stressful circumstances. The findings of the present research are in line with those of Akbarbegloo and Habibpour.^[9] They found a significant correlation between mental health and parents' coping strategies in the case of thalassemia. The results of the present research are in line with those of several others.^[11,12,23-26] The majority of parents, upon hearing about their child's disease, show reactions such as depression, disappointment, guilt, anger, etc.^[23] On the other hand, in any stressful situation with the help of coping strategies one could overcome unadaptable problems.^[24] The present results indicated that parents had a moderate level of mental health. However, these results were contrary to those of Koizumi, which indicated that parents only tolerated anxiety at the beginning of the child's birth and diagnosis of the disease. Later on, they became more tolerant and better able to cope with the disease. To clarify this divergence we could mention the following variables and how they affect the family's mental health and coping strategies: Culture and nationality, family's economic status, supportive services provided by an organization.^[13]

The present research revealed that mother's age (below 40) and her employment is among the risky factors in their mental health. A negative correlation was found between parents' education and their mental health. To clarify this finding, it can be said that parents' life quality is a basic factor affecting their mental health. Moreover, having a child with a chronic disease requires intensive care. In case the mother is employed, she is pressed for time and this would add to their life pressures. It would, therefore, challenge their mental health. Such pressures prevent the growth and development of the family. Furthermore, they expose the family to inefficient coping patterns and pave the way for tense relationships and occupational problems.^[27] This finding was similar to that of Ghazanfari *et al.*,^[20] Sharifi *et al.*,^[28] Akbarbegloo and Habibpour,^[9] Nemat and Shahabzian^[14] and Sharghi *et al.*^[29] On the other hand, the findings of the present research was dissimilar to those of Hashemi *et al.* which indicated the positive effect of high education on effective coping strategies.^[15] In this study, however, no such significant correlation was found. This divergence of findings could be due to factors such as age, gender and income. These factors are effective in promoting the quality-of-life in stressful conditions.^[30] The data presented in Table 3 shows the correlation of coping strategies and general health. The higher the general health is, more compatible the parents are with their child's condition. A great body of previous literature show that parents' of children with chronic diseases suffer from higher levels of stress. Such mental pressure could be with regard with: Concerns about the child's future life, behavioral problems, the child's level of disability, changes in familial relationships, high costs, unachievable dreams, others' pity, society's negative outlook, lack of knowledge, limited access to services and facilities, and conflicts over having another child.^[31,32] An important issue in a family's coping approach is the acceptance of the current status. Coping with the chronic disease plays a key role in reducing spiritual and mental pressures. When the family learn to cope with their child's chronic disease, they can help all the family members including the child to cope with the disease and find the best approaches to control the situation.^[28]

Among the limitations of this study was the low sample size due to lack of access as well as the reluctance of many parents to participate in the research. The findings are not generalizable to all patients of Hormozgan. Another threat to the validity of the responses was the tendency towards responding in a way that was more socially acceptable or preferred by the researcher. More extended research is recommended to be conducted in the other towns of the province hoping to yield more precise and generalizable data. Similar research is also recommended to be carried out in other provinces of Iran.

CONCLUSION

Findings of the present research indicated a significant correlation between the mental health of thalassemic children's parents and their coping strategies. Among the influential demographic factors on coping and mental

health are age, gender and parents' job. It is recommended that in order to help parents who have a thalassemic child to maintain a healthy mental state and cope efficiently with their child's current state, they are provided with consultation services. Provision of such services and guidelines guarantees the mental well-being of the family. Besides these services, the role of thalassemic children supporting centers is also highlighted. They are expected to raise the awareness of families concerning coping strategies and also provide them with the required information about the disease and how to cope with it in the best way.

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