



Coping Behaviors in Parents of Children with Thalassemia major

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Abstract

Background and Aims: Parents of children with thalassemia major, as the main caregivers, encounter numerous challenges in coping with various and complicated problems due to the disease of their children. Although the coping strategies of the parents regarding the illness of their children are of high importance, a few studies have been performed on this subject. Therefore, the present study aimed to determine the coping behaviors of parents of children with thalassemia major.

Methods: This cross-sectional study was performed on parents of 103 children with thalassemia major, who referred to the thalassemia clinic of Hazrat-e-Ali Asghar, Zahedan, Iran in 2016. The data were collected using a demographic questionnaire and the coping health inventory for parents (CHIP). The total score and scores of coping behaviors were evaluated in three coping patterns subscales. The mentioned subscales included “family integration, cooperation, and optimism”, “social support, self-esteem, and mental stability”, and “medical communication and consultation”. All the data were analyzed using descriptive statistics and independent t-test by SPSS version 22.

Results: The coping behaviors that were not mostly carried out by mothers and fathers were “I talk to other parents who are in similar conditions and learn from their experiences” (63.1%) and “I talk to the healthcare team” (73.8%). The mean total score of the CHIP was 51.76 ± 24.65 and 54.79 ± 26.41 for mothers and fathers, respectively. There was no significant difference in the mean total scores and the scores of the three coping patterns between the parents.

Conclusions: According to the findings of this study, the parents achieved scores low than the normal scores in all the three coping behaviors subscales. Effective coping behaviors in the parents of children with thalassemia major seem to be highly important. Consequently, appropriate educational-supportive interventions for parents and continuous monitoring are essential for improving the coping behaviors in this group.

Keywords: Coping Behaviors, Parents, Thalassemia major

1. Background

Thalassemia is the most prevalent genetic disorder of hemoglobin throughout the world. This disease is marked by reduced generation of hemoglobin specific chain and severe anemia. Approximately 80% of the affected people are under the age of 18 years (1, 2). Almost 240 million people have thalassemia major in the whole world and 100 thousand children are born with thalassemia major yearly (3).

Beta thalassemia has been reported in more than 60 countries and is more common in countries that have malaria, such as Iran (4). It is estimated in Egypt that 1000 thalassemia patients are born per 1.5 million people yearly and 6% - 10% of the population are carriers (5). In Pakistan, about 5 - 6 million children suffer from the disease or its symptoms and 5000 children affected with thalassemia are born yearly (6).

Iran is also considered as one of the major regions with prevalent beta thalassemia major, especially in the southern parts, namely Sistan and Baluchistan (7). Approximately 2 - 3 million people are estimated to be carriers of beta-thalassemia and 25,000 patients exist in Iran (8). More than 2000 cases of beta-thalassemia major have been documented in Sistan and Baluchistan province (9). It should be noted that almost 700 billion Rials was reported to pay for patients with thalassemia major yearly (2).

The hereditary nature of this disease, changes in appearance, expecting early death, and need for continuous treatment, impose unfavorable psychological impacts on patients and their families (10, 11). Patients with thalassemia are prone to various psychological disorders (12, 13). According to the findings of a study in Iran, 44% of the children affected by thalassemia major had anxiety and depression and 74% had a low quality of life (14).

Behdadi et al. (2015) demonstrated a higher rate of psy-

chological issues and lower quality of life in children with thalassemia major, compared to their other counterparts (8). However, more than 90% of these children continue their lives even possibly until their fourth decade, if they receive suitable cares (15).

Furthermore, mothers of the children with thalassemia major report a high rate of depression (16). Parents of these patients consider themselves as responsible for the disease of their child leading to a feeling of guilty, hopeless, and worried about the health of their children (7). Results of a study in the United States of America showed that thalassemia had a remarkable impact on mental health of the parents. The literature has reported feelings of anxiety, distress, and hopelessness in parents regarding the conditions of their children, especially blood change and disease progress (17).

A qualitative study was carried out on mothers of children with thalassemia major in Thailand. The authors found lack of knowledge of thalassemia, psychosocial problems, and anxiety about future, social support systems, financial issues, and efficacy of health care services as the problems for this group (18). Another study revealed psychological disorders in 54% of the affected children. In addition, the feeling of shock, fear of death, hopelessness, separation anxiety, and issues concerning concentration and memory were reported in 95% of the parents (19).

In two studies, 60% and 40% of the parents had low knowledge of thalassemia (20, 21). The prevalence of major depression was reported as 11.8% among parents in another study (22). Most parents can successfully cope with chronic diseases. On the other hand, some parents do not succeed in coping, the reasons of which include lack of access to valid information about the disease, lack of proper supportive sources, high treatment costs, mental condition, and social issues (3).

Behrouzian et al. (2013) revealed that 91.2% of the children with thalassemia major suffered from a psychological problem and 80.55% of the mothers used improper coping behaviors. Moreover, a significant positive relationship was found between the improper coping mechanisms of mothers and the psychological problems of their children (23).

Recent studies focus on how the families cope with taking care of their children with chronic or wasting diseases, instead of simply describing the load of taking care. Coping is important because it will help the caring team to support the parents in the best way (24). Parents of the children with thalassemia major encounter various issues with taking care of their children. In order to provide the child and parents with proper cares, it is necessary to understand these problems (25, 26).

More effective and efficient coping behaviors of fathers and mothers can be associated with improved quality of

life of affected children and their family members (4). Coping behaviors include the behaviors and reactions that people express to balance and control the stress caused by different situations. These behaviors are more highlighted in families with ill children and should be enhanced. Better coping leads to raised quality of life in children with thalassemia major (4).

Sistan and Baluchistan ranks first in the birth of neonates with thalassemia major in Iran. Therefore, the identification of effective and ineffective coping behaviors of parents might allow designing suitable educational-supportive interventions. However, most studies have just investigated the coping behaviors of mothers. In addition, no studies have been carried out in this regard in Zahedan, the capital of Sistan and Baluchistan. The current study aimed to determine the coping behaviors of parents of children with thalassemia major.

2. Methods

This cross-sectional study was performed on parents of 103 children with thalassemia major, who referred to the thalassemia clinic of Hazrat-e-Ali Asghar hospital, Zahedan, Iran in 2016. The inclusion criteria entailed: 1) reading and writing literacy, 2) history of at least one year since starting the treatment of thalassemia for the child, 3) living with spouse, 4) not being responsible for taking care of patients other than the thalassemia patient in the family, 5) not being affected by known psychological disorders and, 6) not using psychic medicine.

The data collection tools included a demographic questionnaire and the coping health inventory for parents (CHIP). The demographic data form encompassed gender, the age of the child, duration of being affected by the disease, number of the affected children in the family, the age of the parents, and educational level of the parents. The CHIP was designed by Mccubbin et al. for assessing the coping behaviors in parents of children with chronic diseases as has been used in several studies (4, 27).

This questionnaire addresses 45 coping behaviors with a four-point Likert scale. Parents mark the behaviors they express and determine the benefit of that behavior in coping with the disease of their child on the Likert scale (3 = very beneficial, 2 = almost beneficial, 1 = a little beneficial, 0 = not beneficial). In case the parents had not performed a behavior, they should specify that "it was not possible" or "it was possible but not performed." The coping behaviors of this questionnaire were categorized into three patterns. The "Family integration, cooperation, and optimism", "Social support, self-esteem, and mental stability", and "Medical communication and consultation" patterns included 19, 18, and 8 items, respectively. The scores of coping behaviors are in the range of 0 - 57, 0 - 54, 0 - 24, and 0 - 135 for the

first, second, and third patterns and the whole questionnaire, respectively.

Mccubbin et al. reported the Cronbach's alpha of 0.71 and 0.79 for the internal consistency of this tool. Moreover, these authors provided the "normal scores" as a method for comparison (Table 1) (27-29). Nikfarid et al. carried out the validation of this questionnaire in Iran and confirmed its validity and reliability (27). The reliability of the tool was assessed by Cronbach's alpha of 0.71 in the present study.

Informed consent was taken from the parents and the researchers explained the aims of the study. The participants were assured regarding data confidentiality and then, they completed the questionnaires. The individuals were asked to answer the questionnaires in the next blood transfusion session in case they were not present. All the data were analyzed by descriptive statistics (frequency distribution, mean, and standard deviation) and independent t-test using SPSS version 22. Normality of the data distribution was confirmed by Kolmogorov-Smirnov test.

3. Results

According to the findings, the mean age of the parents and children was 33.42 ± 9.62 and 8.42 ± 6.46 years, respectively. Moreover, it was found that 24.3% of the parents had an education level of high school diploma or higher and 57.3% of the children were female. The mean duration of the disease was 6.99 ± 5.09 years.

As demonstrated in Table 2, the mean total score of CHIP was 51.76 ± 24.65 and 54.79 ± 26.41 for mothers and fathers, respectively. The mean scores of the parents had significant differences with each other regarding none of the three behavioral patterns and the total score. Furthermore, there was no significant relationship between the demographic data and the total score of coping behaviors of the parents.

Table 3 indicates the most performed coping behaviors by mothers and fathers for each subscale. For the subscale "Family integration, cooperation, and optimism," the items of "I read more about the medical issues that worry me" (76.8%) and "I talk to people other than the treatment team" (70.9%) were expressed the most. Regarding the subscale "Social support, self-esteem, and mental stability," the most common coping behavior in mothers and fathers was "I turn to god" with frequencies of 76.8% and 70.9%, respectively. In addition, considering the "Medical communication and consultation" subscale, mothers and fathers chose "I say I have things that I should thank god for" with the frequencies of 64.1% and 69.9%, respectively.

As Table 4 shows, the least performed behaviors for mothers and fathers in the subscale "Family integration, cooperation, and optimism" were "I talk to the other parents who have my conditions and I learn from their ex-

periences" (63.1%) and "I talk to the health care providers (e.g. nurses, social workers)" (73.8%). Concerning the "Social support, self-esteem, and mental stability" subscale, the least expressed statements included "I develop myself as a human" (51.4%) and "I work extra in my workplace after the working hours" (64.1%). In addition, the least common coping behaviors in the subscale "Medical communication and consultation" were found to be "I go out with my husband/wife as usual" (47.6%) and "I let myself get angry" (58.2%).

4. Discussion

According to the results of the present study, the mean scores of parents did not have significant differences with each other regarding any of the three subscales of behavioral patterns and the total score. In addition, the parents obtained low scores in all the three patterns of coping behaviors in comparison with the normal scores.

These findings demonstrate that most of the parents did not have effective and efficient coping behaviors. Costs, stress, and fear of death account for the mental pressure in the parents of children with thalassemia major. A cross-sectional study of 35 parents indicated that 60.6% were experiencing stress (30). Thalassemia is associated with numerous challenges for the patients and their families concerning the physical, mental, and cognitive aspects, all of which might disturb their psychosocial life (31, 32).

In the current study, the most expressed coping behaviors by mothers and fathers included "I read more about the medical problems that worry me and turn to god" and "I show that I am strong." The mentioned results are consistent with the study of Nikfarid et al. (2011) that reported "I pray" as the most common coping behavior in mothers (27).

Furthermore, Yazdi et al. (2007) concluded that mothers (33) mostly applied belief and trust in God. These findings demonstrate the role of spirituality in the effective coping with problems caused by the disease that is not surprising considering the religious and cultural bases of Iran. Therefore, it seems that influential spiritual support for these parents should be included in the interventional-supportive programs of the treatment team, especially the nurses.

The least performed coping behaviors were "I talk to the other parents who have my conditions and I learn from their experiences" and "I talk to the treatment team." In the study of Yazdi et al. (2007), receiving social support was found to have the least frequency (33). Pouraboli et al. (2017) also revealed the lack of supportive network as one of the important factors of the increase in caring load and lack of suitable coping with the disease of children affected by thalassemia major (26). All these findings demonstrate

Table 1. Normal Scores of Coping Patterns in Parents of Children with Chronic Diseases on Coping Health Inventory for Parents

Behavioral Pattern	Mothers		Fathers	
	Mean \pm SD	Range	Mean \pm SD	Range
Family integration, cooperation, and optimism	40 \pm 15	25 - 55	36 \pm 20	16 - 56
Social support, self-esteem, and mental stability	28 \pm 12	16 - 40	25 \pm 15	10 - 41
Medical communication and consultation	15 \pm 7	8 - 22	12 \pm 8	4 - 19

Table 2. Comparison of the Mean Total Scores and the Means of Coping Health Inventory for Parents^a

Behavioral Subscales	Mothers	Fathers	P Value	t	df
Family integration, cooperation, and optimism	21.90 \pm 11.46	22.12 \pm 12.74	0.27	1.1	204
Social support, self-esteem, and mental stability	20.93 \pm 9.97	22.62 \pm 11.89	0.27	1.1	204
Medical communication and consultation	8.95 \pm 4.57	10.04 \pm 4.79	0.09	1.68	204
Total score	51.76 \pm 24.65	54.79 \pm 26.41	0.39	0.84	204

^aValues are expressed as mean \pm SD.

Table 3. Some of the Most Common Coping Behaviors Expressed by the Parents

	Mothers		Fathers	
	Item	No. (%)	Item	No. (%)
Family integration, cooperation, and optimism	I read more about the medical issues that worry me	79 (76.8)	I talk to people other than the treatment team	73 (70.9)
	I made more intimate relationships with my husband	52 (50.5)	I made more intimate relationships with my wife	59 (57.3)
	I talk to people other than the treatment team	47 (45.5)	I make close relationships with people	54 (52.4)
	I cooperate with all the family members for things like cleaning the house	40 (48.5)	I cooperate with all the family members for things like cleaning the house	48 (46.6)
Social support, self-esteem, and mental stability	I turn to god	79 (76.8)	I turn to god	73 (70.9)
	I bring my child to the hospital regularly for controlling his/her status	60 (58.2)	I try to stabilize the family	58 (56.3)
	I encourage my ill child to be independent	56 (53.5)	I believe that my wife supports me and my child	63 (51.1)
Medical communication and consultation	I invite my friends	55 (53.4)	I encourage my ill child to be independent	47 (45.5)
	I say that I have things to thank god for	64 (64.1)	I say that I have things to thank god for	72 (69.9)
	I show that I am strong	59 (57.3)	I show that I am strong	75 (72.8)
	I take care of the medical facilities and medications of my child at home	41 (39.8)	I believe that my child receives the best medical facilities and services	45 (43.7)
	I believe that my child receives the best medical facilities and services	38 (36.9)	I take care of the medical facilities and medications of my child at home	40 (38.8)

the poor relationships between the parents and treatment team, including the doctors and nurses, for obtaining information, required support, and enhancing the abilities for taking care of children.

The members of the health and therapeutic services team should design and execute suitable interventions based on effective communications through identifying the educational and supportive needs of parents. Providing information leads parents to manage the disease of

their children more adequately (34). The improper coping behaviors of the parents result in unfavorable effects on managing the disease of their children and following the treatments (35). The people in charge and nurses should help the parents to enhance their management ability by consultations and administration of suitable interventions (10, 36).

The results of our study demonstrated that reduced social and recreational activities, as well as reduced relation-

Table 4. Some of the Least Common Coping Behaviors Expressed by the Parents

	Mothers		Fathers	
	Statement	No. (%)	Statement	No. (%)
Family integration, cooperation, and optimism	I talk to other parents who have my conditions and I learn from their experiences	65 (63.1)	I talk to the treatment team	76 (73.8)
	I talk to the doctor about the problems of my child	60 (58.2)	I talk to the doctor about medical anxieties of my child	75 (72.8)
	In order to rest, I spend short times out of the home and far from the responsibilities	44 (42.7)	I talk to the other parents who have my conditions and I learn from their experiences	43 (41.7)
	I eat a lot	43 (41.7)	I work extra after the working hours	42 (40.8)
Social support, self-esteem, and mental stability	I develop myself as a human	53 (51.4)	I work extra after the working hours	66 (64.1)
	We do group works with relatives and family members	50 (48.6)	I spend my time and energy at work	65 (64)
	I focus on my favorite leisure activities, such as music, cinema, and reading	49 (47.6)	I focus on my favorite leisure activities, such as music, cinema, and reading	60 (58.2)
Medical communication and consultation	When I go to the medical center, I talk to the medical staff	45 (43.7)	I invite my friends to my house	47 (45.5)
	I go out with my spouse regularly	49 (47.6)	I let myself get angry	60 (58.2)
	I let myself get angry	48 (46.6)	I have social activities with my friends, such as party and sports	59 (57.3)
	I have social activities with my friends, such as party and sports	37 (35.9)	I go out with my spouse regularly	40 (38.8)
	I take care of the medical facilities at home	35 (33.9)	I read about how the people in similar conditions face the issues	38 (36.9)

ships with spouse and relatives, were among the coping behaviors, which were less expressed by the parents following the disease of their children. The latter findings are in line with numerous previous studies (4, 27, 33).

Furthermore, the findings indicate that the disease of a child is accompanied by a poor supportive network of the parents, including spouse, relatives, and friends. However, the improvement of these relationships plays an important role in better and more effective coping behaviors of the parents, as well as diminished psychological load and caring problem. As a result, providers of health and therapeutic cares must consider enhancing all these factors.

In the present study, no significant relationship was observed between the demographic data of the parents and the characteristics of child's disease in the CHIP. This result is consistent with the findings of Nikfarid et al. (2011) (27). It should be noted that studies with larger sample sizes are required for a more accurate analysis.

It could be concluded from the findings of the current study that there is no significant difference in the patterns of coping between the parents of thalassemia major children. This is the first study comparing the coping behaviors between the parents. Consequently, further investigations are recommended for interpreting the results and the reasons for differences or indifferences in the coping

behaviors of the parents of children with chronic diseases.

The limited sample size and performing the study in only one clinic of Zahedan could be mentioned as the limitations of the present study. Therefore, the results should be generalized cautiously.

4.1. Conclusions

According to the findings of this study, parents gained scores lower than the normal scores in all the three patterns of coping behaviors. Employing proper educational-supportive interventions in caring programs of the children with thalassemia seems to be necessary for improving the coping behaviors of the parents.

For future studies, suitable interventions focusing on the enhancement of supportive-informative sources available for the parents are recommended. The efficacy of these methods in improving the coping behaviors of the parents and the quality of cares for the children with thalassemia major should be further evaluated.

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