

Coping Strategies in Patients with Beta-thalassemia and their Parents: A Systematic Review

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Abstract

Background: Thalassemia is one of the most common genetic disorders. Patients with thalassemia and their families face various challenges in their daily lives, which affect their coping strategies. The aim of this study was to evaluate the coping strategies in patients with beta-thalassemia and their parents.

Methods: The present systematic review examines the coping strategies applied by the thalassemic patients and their caregivers. We carried out electronic searches using Medline (via PubMed), Web of science, and Scopus to select the related studies without date restriction until Nov, 10, 2021; and completed the findings by hand search. The Mesh-based search terms were Beta thalassemia, Mediterranean anemia, Cooley anemia, coping, and adaptation.

Results: The electronic search process identified 311 papers as candidates for the systematic review. After applying the inclusion and exclusion criteria, 9 articles remained for analysis. The review of the 9 articles showed that the patients with beta-thalassemia use emotion-focused coping strategies in the form of distraction and avoidance coping strategies to deal with their problems. Also, religious coping is the most coping strategy which is used by the parents. Furthermore, there is a positive relation between adaptive coping strategies and quality of life and resilience.

Conclusions: According to the results, patients with beta-thalassemia use maladaptive coping skills (emotion-focused coping strategies). Also the evaluated studies demonstrated that using the adaptive coping strategies improved the quality of life, resilience and psychological health of patients with thalassemia and their caregivers.

Key Words: Adaptation, Beta-thalassemia, Coping, Parent.

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1- INTRODUCTION

Thalassemia is a genetic blood disorder, in which globin chain production is reduced or not produced (1). The World Health Organization (WHO) identifies thalassemia as the most common genetic blood disorder, in more than 60 countries with a population of more than 150 million people (1). Beta-thalassemia is a type of thalassemia caused by a decrease or failure in the synthesis of the beta-globin chain (2). Beta-thalassemia is an inherited congenital hemoglobinopathy (3). The prevalence of β -thalassemia is usually high in the Mediterranean region, the Middle East, and Southeast Asia (1). Due to migration patterns, β -thalassemia is also increasingly more common in non-endemic regions, including Western Europe and North America (4). Iran is a Middle-Eastern country located on the thalassemia belt with approximately 26,000 patients suffering from thalassemia and its prevalence is 2.5-15% in different regions of the country (5). Considering the importance of preventing hemoglobinopathies, WHO has prioritized beta-thalassemia, in developing countries (6).

Beta-thalassemia is a chronic condition, which puts a huge psychosocial burden on the patient and his family (7). Patients with beta-thalassemia suffer from a variety of physical and psychological problems, including growth retardation, delayed puberty, and physical deformities which consequently lead to a poor self-image and low self-esteem (3). Also, they can be susceptible to depression and anxiety owing to societal issues like family separation, facial and physical malformations, anxiety of death, and limitations in play and school activities (8). In addition, parents of the patients with beta-thalassemia undergo significant psychological problems, causing emotional burden, hopelessness, and difficulty with social integration (9). They have severe

psychosocial problems due to their inability to cope up with the painful situation which leads to worsening the relationships amongst family members, and increasing marginalization and isolation (9).

Coping has been outlined as a response to reduce the physical, psychological and emotional burden that is associated with stressful life events (8), (10). Coping strategies are defined as constantly changing cognitive and behavioral efforts to manage specific external or internal demands that are far beyond the existing resources of the person (11). Based on psychological theories, these strategies play an important role in managing stressful situations, reducing stress, and ultimately in mental health along with the psychological and physical well-being of the individuals (1). Although coping strategies, either active or inactive, include a set of efforts which individuals make to avoid health threatening factors, using any one of these styles does not necessarily lead to the reduction of psychological factors; sometimes they not only do not reduce the stress, but also increase it (1). The results of various studies indicate that due to some maladaptive copings, the children's conditions and their quality of life is negatively affected (1).

Despite the importance of coping with beta-thalassemia, few articles assessed coping strategies in patients with beta thalassemia and their families. Therefore, this systematic review was performed to investigate the coping strategies in patients with Beta-Thalassemia and their parents.

2- Materials and METHODS

2-1. Method

The present systematic review used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology. We assess the coping strategies of the patients with beta-thalassemia and their parents based on the

Joanna Briggs Institute (JBI) critical appraisal checklist.

We carried out electronic searches using Medline (via PubMed), Scopus, and Web of Science without date restriction until Nov, 10, 2021 and completed the findings by hand search. The Mesh-based search terms were Beta-thalassemia,

Mediterranean anemia, Cooley anemia, coping, and adaptation (**Table 1**). This search process on English articles was done by two of the authors; and two reviewers used checklists to appraise both quantitative and qualitative evidence. In cases that the reviewers did not reach an agreement, a third reviewer was consulted.

Table-1: Databases, keywords, and search history.

Data base	Searched date	Key words	Articles retrieved
MEDLINE (via PubMed)	Nov, 10, 2021	((beta- thalassemia) OR (Mediterranean anemia) OR (Cooley anemia)) AND ((coping) OR (adaptation))	135
Scopus	Nov, 10, 2021	(TITLE-ABS-KEY (beta AND thalassemia) OR TITLE-ABS-KEY (mediterranean AND anemia) OR TITLE-ABS-KEY (cooley AND anemia) AND TITLE-ABS-KEY (coping) OR TITLE-ABS-KEY (adaptation))	107
Web of Science	Nov, 10, 2021	Beta- thalassemia (topic) AND coping (topic), Beta- thalassemia (topic) AND adaptation (topic), Mediterranean anemia (topic) AND coping (topic), Mediterranean anemia(topic) AND adaptation (topic), Cooley anemia(topic) AND coping(topic), Cooley anemia (topic) AND adaptation (topic)	68

Coping strategies in patients with beta-thalassemia and their families were systematically reviewed based on the JBI critical appraisal checklists (12). These are independent checklists for cross-sectional and case-control studies, with 8 and 10 questions, respectively. Each question is answered by yes, no, unclear, and not applicable; and the overall appraisal is shown by include, exclude, and seek for more information. The articles which had the most yes answers ($\geq 50\%$) and the overall appraisal of inclusion entered into the study.

The electronic search process identified 311 papers as candidates of the systematic review, including 136 articles in Medline,

107 in Scopus, and 68 in Web of Science. After removing duplicates and incompatible articles (diseases other than beta-thalassemia, no coping strategies assessment), 20 articles remained and 7 studies were added by hand search. Eventually, after studying the abstracts and the full texts, based on the inclusion and exclusion criteria, only 9 articles left for the analysis (**Fig. 1**).

2-2. Inclusion and exclusion criteria

The inclusion criteria included the quantitative studies (cross-sectional, correlation, case control) on coping strategies of patients with beta-thalassemia, published in the English language.

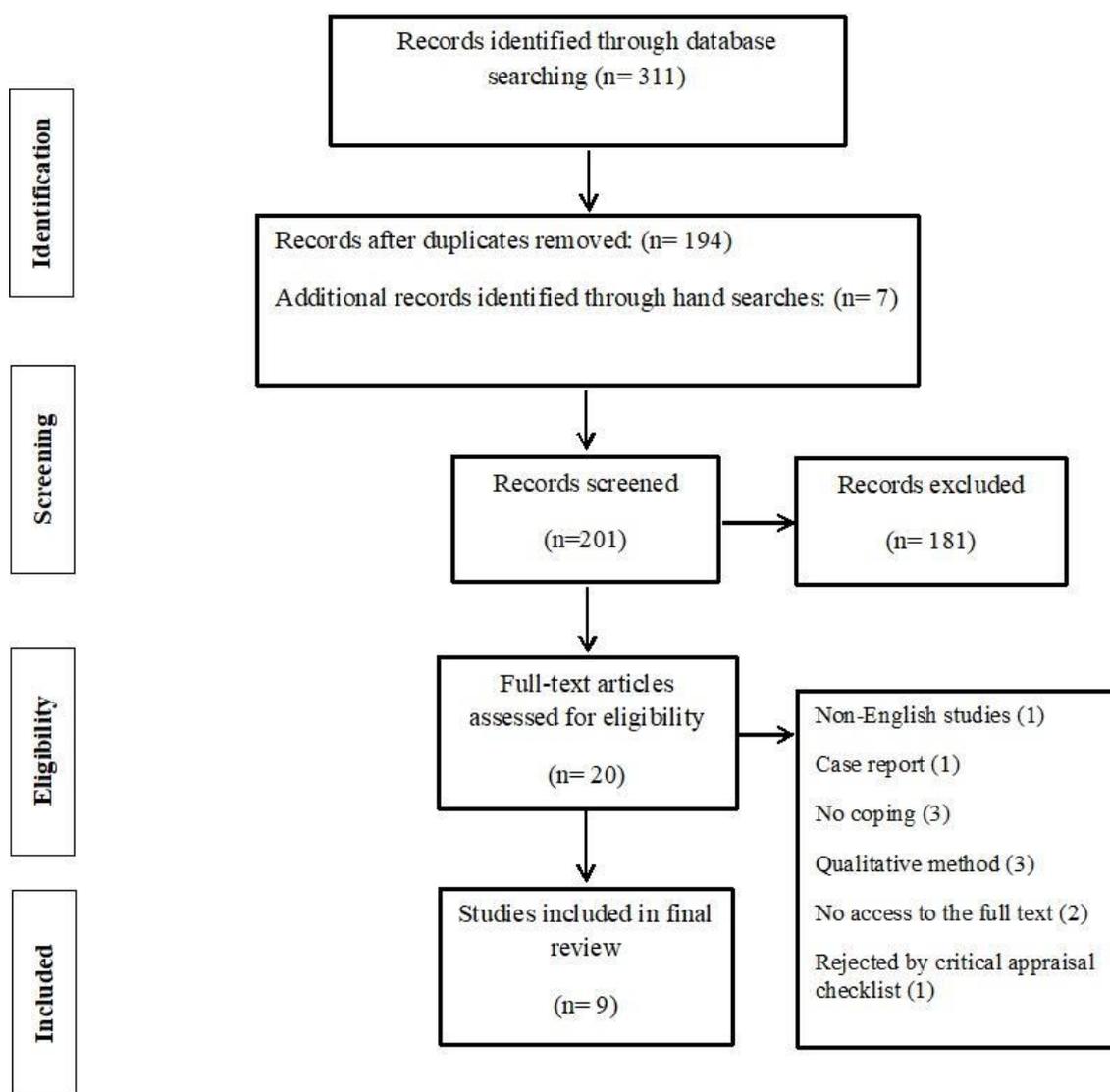


Fig.1: Process of searching and selecting articles for the analysis

We excluded studies assessing patients with diseases other than beta-thalassemia; those with no accessible full text; published abstracts in congress, seminar, or conference-booklets; letter to the editors; and also short reports, case reports, and mixed method designs, systematic reviews, meta-analysis, validation of instruments, articles without a patient sample and qualitative studies.

2-3. Ethical considerations

This study is a part of a master's thesis in pediatric nursing with the code of ethics IR.MUMS.NURSE.REC.1400.017.

2-4. Data extractions

All titles and abstracts were screened by two independent reviewers; whenever the information present in the abstract was not enough to identify the inclusion and exclusion criteria, the full text was retrieved. We then independently assessed each selected paper for detailed evaluation. Two reviewers also independently extracted relevant trial characteristics, and had consensus meetings to discuss their decisions regarding the inclusion or exclusion of the articles; and in cases of disagreement, a third author was

consulted. Two reviewers independently appraised the quality of included articles

based on their type in JBI appraisal checklists (**Table 2**).

Table-2: Critical appraisal of articles

First Authors, Year	Design	Score	Decision
Abbasi, 2020	Case-control	7/10 (7 yes of 10 questions)	Include
Messina, 2008	Cross-sectional	4/8 (4 yes of 8 questions)	Include
Parviniannasab, 2021	Cross-sectional	7/8 (7 yes of 8 questions)	Include
Ali, 2018	Cross-sectional	6/8 (6 yes of 8 questions)	Include
Fung,2008	Cross-sectional	3/8 (3 yes of 8 questions)	Exclude
Zani,2013	Case-control	8/10 (8 yes of 10 questions)	Include
Chong, 2019	Cross-sectional	6/8 (6 yes of 8 questions)	Include
Kermansarvari,2018	Cross-sectional	6/8 (6 yes of 8 questions)	Include
Ali, 2012	Cross-sectional	4/8 (4 yes of 8 questions)	Include
Dadipoor. 2013	Cross-sectional	7/8 (7 yes of 8 questions)	Include

3- RESULTS

The search yielded 311 articles, including 136 articles in Medline, 107 in Scopus, and 68 in Web of Science. Once 117 duplicates were removed, 7 studies were manually added. Then 201 articles were screened according to their titles and abstracts and those related to coping skills and strategies used by the patients with beta thalassemia were selected. Finally, after applying the inclusion and exclusion criteria, 9 articles were remained (**Fig. 1**)

3-1. Definition of coping

All the analyzed studies defined coping as the process by which the person tries to manage stress (8).

3-2. Design of the studies

We found 9 studies with 7 cross-sectional designs (5, 8, 9, 13-16) and 2 case control studies (1), (17).

3-3. Coping strategies

Five studies assessed coping strategies in patients with beta-thalassemia (1, 5, 8, 13, 17) and four investigated coping skills in their parents (9, 14-16) (**Table 3**).

3-4. The patients' coping strategies

The most commonly used coping strategies were emotion and avoidance-oriented coping strategies (1, 13, 5, 8) and the least used coping strategies were: accepting responsibility (13), problem solving (13), positive reappraisal (13), and seeking social support (5). However a study indicated that the most prevalent coping strategies were active coping and the least prevalent coping skills were avoidance coping (17).

Moreover, the studies demonstrated that the selection of coping strategies is related to age (8), educational level (8), gender (5, 8) and duration of illness (8). Also, the findings showed that the patients with thalassemia have a lower quality of life (1), mental health (1), self-image (13) and social functioning (1, 13) and they suffer from psychiatric disorders (13).

3-5. The parents' coping strategies

The most expressed coping behaviors applied by the parents of the thalassemia patients included positive religious coping methods (14), "turning to god" (15, 16), "reading more about the medical problems that worried them" (17), "presenting

themselves as strong individuals”(15) and active coping (9).

One study manifested that the least performed behaviors by the parents were “talking to the other parents who had the same conditions and learning from their experiences”, “developing their own capabilities and interests”, “going out with their spouse as usual” and “letting themselves get angry”(17) and substance use (9). Another study indicated that they use positive religious coping more than negative religious coping skills (14). Moreover, a significant correlation was found between the parents’ coping strategies and their mental health (16). In addition, some studies had found that the parents experienced psychological distress (14, 9).

4- DISCUSSION

In this systematic review some coping skills were assessed. In general, the patients with beta-thalassemia used a maladaptive coping style (emotion and avoidance-oriented coping). Also, the studies indicated the efficacy of coping strategies in ameliorating the quality of life, resilience and psychological health of the patients with thalassemia and their caregivers.

4-1. The patients’ coping skills

Abbasi et al. (1), studied the relationship between different aspects of quality of life and the coping styles in the adolescents with thalassemia in comparison to a healthy control group. They found that the adolescents with thalassemia were more likely to use emotion and avoidance-oriented coping styles than the control group. The findings, further, revealed that the adolescents with thalassemia have a lower quality of life, mental health and environmental relationships than the healthy ones. The study also indicated that there is a negative relationship between the emotion- oriented coping style and the quality of life and physical health of the

patients. However, there is a direct relationship between the emotion-oriented coping style and the social dimension of the quality of life. On the other hand, when the task-oriented coping style was used more, the quality of life, social relationships and physical health in adolescents with thalassemia increased.

Messina et al. (13), assessed the self-image, the quality of life, and the way of coping and the existence of psychiatric disorders in young adults with thalassemia major. The study indicated that 80% of the patients with thalassemia major had low self-images and their identities were integrated with the feeling of insufficiency. The findings manifested that most of the patients have difficult social relationships. Moreover, the study demonstrated that thirty percent of the patients with thalassemia major had at least one psychiatric disorder. They suffered from depression, obsessive-compulsive traits, and somatic symptom disorders. Furthermore, the principal coping strategy used was Escape-avoidance and the least used coping skills were Accepting responsibility, Problem solving and Positive reappraisal.

Parviniannasab et al. (5), conducted a study regarding the association of coping strategies with resilience among adolescents with beta-thalassemia major. Based on the findings, the boys used courageous coping (confrontive, optimistic, and supportant) and defensive coping (emotive and evasive) strategies, slightly, more than girls. The results of the study revealed that courageous coping (especially optimistic) is effective in promoting resilience; and defensive coping, on the other hand, leads to less resilience than the optimal level. Moreover, becoming evasive is the most commonly used coping skill, while choosing to be supportant is the least used strategy in adolescents with beta-thalassemia.

Table-3: Description of the coping skills

First Author, Year	Sample	Design	Instrument	Objective	Findings
Abbasi, 2020	200 adolescents in 2 groups: 100 adolescents with beta- thalassemia and 100 healthy adolescents	Case-control	1. Endler and Parker's coping style questionnaire 2. WHOQOL (World Health Organization's Quality of Life questionnaire) - BREF questionnaire	Determining the relation between different aspects of quality of life with coping styles in the adolescents with thalassemia in comparison to a healthy control group	Adolescents with thalassemia were more likely to use emotion and avoidance-oriented coping styles than those in the control group.
Messina, 2008	147 patients with beta-thalassemia	Cross-sectional	1. The Ways of Coping Questionnaire (WCQ). 2. The Machover's test. 3. The Short Form 36 health survey questionnaire (SF-36). 4. Symptom-checklist-90 revised (SCL-90-R)	Assessing the self-image, the quality of life, the way of coping and investigating the existence of psychiatric disorders in young adults with thalassemia major	The principal coping strategy Used as escape-avoidance.
Parviniannasab, 2021	134 adolescents with beta- thalassemia major	Correlational	1. Jalowiec Coping scale 2. Connor-Davidson resilience scale	Investigating the relationship between coping strategies and resilience among adolescents with beta-thalassemia major	Evasiveness is the most commonly used and supporting is the least used coping skill.
Ali, 2018	300 of children with thalassemia	Cross-sectional	1. Children's Coping Strategies Checklist-Revision 1 (CCSC- R1).	Evaluating the prevalence of coping strategies among children with thalassemia	Avoidance and distraction strategies (Emotion-focused) Are the most commonly used coping strategies.

<p>Zani, 2015</p>	<p>158 patients with beta thalassemia major, 85 beta-thalassemia major participants and 73 Controls</p>	<p>Case-control</p>	<ol style="list-style-type: none"> 1. The 36-item scale of Adolescent Coping Orientation for Problem Experiences scale (A-COPE; Patterson and McCubbin, 1987) 2. 10-item Rosenberg self-esteem scale (Prezza et al., 1997) 3. Single-item overall measure (see Wanous et al., 1997) 4. The short-form-36 health survey scale (Ware and Sherbourne, 1992) 	<p>Comparing the psychosocial functioning of a sample of adults with beta-thalassemia major to that of a control sample and examining the protective role of the quality of relationship with parents during adolescence and perceived quality of care</p>	<p>The most used coping strategies are the positive emotion, an active way of coping and support from friends. The least used coping strategy is avoidance coping.</p>
<p>Chong, 2019</p>	<p>162 parents of the children with thalassemia</p>	<p>Cross-sectional</p>	<ol style="list-style-type: none"> 1. Brief RCOPE questionnaire 	<p>Examining the relationship between religious practice, religious coping methods and psychological distress among parents caring for children with transfusion-dependent thalassemia</p>	<p>They used positive religious coping methods more than negative religious coping methods.</p>
<p>Kermansaravi, 2018</p>	<p>Parents of 103 children with thalassemia major</p>	<p>Cross-sectional</p>	<ol style="list-style-type: none"> 1. Coping health inventory for parents 	<p>Determining the coping behaviors among the parents of children with thalassemia major</p>	<p>The most expressed coping behaviors by the parents included “reading more about the medical problems that worried them and turning to god” and “presenting themselves as strong individuals.”</p>

Ali,2012	40 Parents of beta-thalassemia Major Patients (17 Fathers, 23 mothers)	Cross-sectional	1. Brief COPE by Carver 1997	Assessing the psychological well-being among the parents of the children with thalassemia	The most commonly used coping strategies were Active coping (97.5%), Planning (95%), Acceptance (92.5%), Religion (92.5%), self-blame (92.5), Using the instrumental support (90%), Positive reframing (87.5%), and Self-Distraction (82.5%). Others included the Use of emotional support (73%), Venting (70%), Behavioral disengagement (62.5%) and Denial (60%). The least used coping strategies included humor (15%), and substance use (7.5%).
Dadipoor, 2015	140 parents of the children with major thalassemia	Cross-sectional	1. General Health Questionnaire 2. Coping strategies questionnaire by Ghazanfari et al.	Investigating the mental health and coping Strategies used by the families of the children with major thalassemia in Bandar Abbas in 2013	The most prevalent coping strategies among the parents were represented as: “trust in God in order to get his/her problems solved” (87%), “to get mentally and spiritually relieved, visit mosques and holy shrines” (53%), and “making harder attempts to overcome problems” (50.7%).

Ali et al. (2018) (8), studied coping strategies among children with thalassemia. The findings of the study indicated that the most commonly used coping skills by the children with thalassemia were distraction and avoidance coping strategies (maladaptive or emotion-focused coping).

In other words, many of the children with thalassemia prefer to avoid thinking about the problematic situation by staying away from it or leaving it or physically working off their feelings with physical exercise, play or efforts to physically relax. Additionally, they found that applying the coping strategies was related to the duration of illness, age, educational level and gender. Lower educational levels, younger ages and lower disease durations were related to the more uses of coping strategies. They showed that the female children used more coping strategies than the males hospitalized with thalassemia; however, parviniannasab et al. (5) indicated that the boys used the coping skills, slightly, more than the female adolescents did.

Fung et al. (18), revealed that the coping strategies varied with different developmental stages. The younger subjects preferred more active forms of coping and had a stronger reliance on seeking help from others. However, older subjects tended to use more cognitive strategies. They tried to cope with their negative mood by adopting more positive thinking. These differences in coping strategies may reflect diversities in the nature of problems which people encountered in different ages.

Zani et al. (17), compared the psychosocial functioning of a sample of adults with beta-thalassemia major to a control sample of healthy participants. The most used coping strategy is the positive emotion, an active way of coping and support from friends ($\alpha = .77$) and the least used coping skill is avoidance coping ($\alpha = .63$). They

did not find any significant differences between the two groups on the five dimensions of coping. Also, they showed that there were no differences between the two groups in terms of the participants' relationship with parents, family and friends, romantic and sexual relationships and general body image. The patients with beta-thalassemia major described themselves in positive terms, particularly as calmer, emotionally stronger and more sociable than the control group. Additionally, they reported a poorer health status compared to their healthy controls.

4-2. The parents' coping strategies

Chong et al. (14), examined the relationship between religious practice, religious coping methods and psychological distress among the parents caring for children with transfusion-dependent thalassemia. The study findings showed that the parents experienced a lot of psychological distress. Among the main coping mechanisms that they used to deal with their psychological discomfort were the positive and negative religious coping (14). Positive religious coping is a more optimistic style of coping, which involves forgiveness, seeking spiritual support, collaborative religious coping, spiritual connection, religious purification, and benevolent religious reappraisal (19). Negative religious coping patterns are a more pessimistic style of coping, involving spiritual discontent, believing in the punishing God reappraisals and demonic reappraisals, interpersonal religious discontent, and reappraisal of God's powers (19). The study demonstrated that the parents of children with thalassemia used positive religious copings more than negative religious coping methods. Also, Psychological distress was significantly related to organize religious activities, non-organized religious activities as well as the positive and negative religious coping methods. Moreover, the findings indicated that the parents who often used

negative religious coping methods tended to have more psychological distress than those using positive religious coping methods.

Kermansarvari et al. (15), investigated the coping behaviors of the parents of children with thalassemia major. They found that the most expressed coping behaviors by the mothers and fathers were as follows: "I read more about the medical issues that worry me", "I turn to god" and "I show that I am strong". Furthermore, the article showed that the least performed behaviors by the parents were the following: "I talk to the other parents who have my conditions and I learn from their experiences", "I develop myself as a human", "I go out with my husband/wife as usual" and "I let myself get angry". The findings indicated that the parents obtained low scores in coping behaviors in comparison with the normal scores. As a result, most of the parents did not have effective and efficient coping behaviors.

Ali et al. (9), assessed the psychological distress and coping strategies of the parents of children with thalassemia. This study showed that all the parents had severe parental stress and used different coping skills. In addition, the mothers were found to have more distress than fathers. The most commonly used coping strategies were active coping (97.5%), planning (95%), acceptance (92.5%), religion (92.5%), self-blame (92.5%), use of instrumental support (90%), positive reframing (87.5%), and self-distraction (82.5%). The least used coping strategies included humor (15%), and substance use (7.5%). Moreover, the findings manifested that the coping strategies of Denial and Behavioral disengagement were more prevalent among the fathers. In Other words, it was difficult for fathers to accept their child's disease and denied it completely.

Dadipoor et al. (16), investigated the mental health and coping strategies of

families with children suffering from major thalassemia in Bandar Abbas in 2013. According to the findings of this study, the most prevalent coping strategies among the parents were represented as: "I trust in God in order to get my problems solved", "to get mentally and spiritually relieved, I would visit mosques and holy shrines", and "to overcome problems, I make harder attempts". Also, there was a positive relation between the mental health and coping strategies of the parents. Furthermore, a significant correlation was also observed between the mother's educational level, age, the parents' job and their general health. The present research revealed that the mother's age (below 40) and her employment is among the risky factors in their mental health. A negative correlation was found between the parents' education and their mental health.

5- LIMITATIONS

The main limitation of this systematic review is that we only searched in databases of Medline (via PubMed), Scopus and Web of science and the other databases were not searched.

6- CONCLUSION

According to the results of this study, the patients with beta-thalassemia tend to use maladaptive coping skills (emotion-focused coping strategies) in the form of distraction and avoidance coping strategies to deal with distress. Furthermore, they showed that using adaptive coping strategies improved the quality of life, resilience and psychological health of the patients with thalassemia and their caregivers. Hence, understanding the importance and role of the coping strategies in patients with beta-thalassemia major can help the health managers and health care providers in planning some effective interventions to increase the coping skills in these patients for improving their ability in dealing with problems.

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