

Conference Paper

Psychosocial Problems on Adolescents with Thalassemia Major: A Systematic Scoping Review

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Abstract.

Disease and treatment of thalassemia major that are carried out for life can cause physical and psychological problems in sufferers. Adolescents with thalassemia major will experience disturbances at a stage of development that is undergoing dynamic changes. Nurses, as health workers who provide holistic services, need to know what psychosocial problems may arise in adolescents with thalassemia major. This study aims to describe psychosocial problems in adolescents with thalassemia major. This study uses a scoping review design by searching English literature through the CINAHL, PubMed, and Scopus databases. The keywords used are psychosocial problems, thalassemia major, and adolescence. The criteria for the article in this study where the patient was a teenager with thalassemia, open access full text, and the time setting was the last 10 years (2013-2022). We found 9 articles discussing psychosocial problems in adolescents with thalassemia. Psychosocial problems that arise in the form of disturbances in several functions, namely physical, emotional, social, and school functions. Psychosocial disorders that occur in adolescents with thalassemia cause disturbances at the stage of adolescent development. Psychosocial problems that occur in adolescents with thalassemia include impaired physical, emotional, social, and school functions.

Keywords: adolescence, psychosocial problems, thalassemia major

1. Introduction

Thalassemia is an inherited blood disorder caused by a defect in the gene responsible for producing the globin chains in hemoglobin (1). According to World Bank data, 7% of the world's population is a carrier (carrier) of thalassemia. The World Health Organization states that 7% of the world's population with thalassemia genes and 40% of them occur in Asia [1]. Every year, around 50,000-100,000 children die from -thalassemia, of which

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around 80% of them come from developing countries including Indonesia, which is a country with a high frequency of thalassemia carrier genes. Approximately 1.5% of the global population are carriers of thalassemia. Approximately 50,000-100,000 children die of thalassemia major, and at least 3000 die each year in their teens or early 20s from uncontrolled iron overload. This condition occurs 90% in low-income or developing countries [2]–[4].

Thalassemia major requires ongoing treatment and care because thalassemia cannot be cured [5]. Treatment is given in the form of blood transfusions to maintain hemoglobin levels above 10g/dl [6]. In children aged 5 years and over with thalassemia disease will cause blood transfusions to be given to the child throughout his life [7]. Thalassemia disease and treatment that is carried out over the long term can have a negative impact on the sufferer [8].

The negative impact will be more severe in adolescents, namely when they seek autonomy for themselves [9]. The adolescent phase is a transitional phase from childhood to adulthood that will cause dynamic psychological and social changes. Adolescents with thalassemia will face emotional feelings such as sudden mood swings. This is in line with the results of research conducted by Behdani et al (2015), adolescents who suffer from thalassemia major experience more psychological, emotional, and social behavior problems that are worse than healthy adolescents ($p < 0.001$) [10].

The negative impact of thalassemia major treatment can affect the appearance of adolescents such as bone deformities and short stature [11]. In addition, treatment also has an impact on Cooley's facies such as causing slanted eyes, protrusion of the forehead, the distance between the two eyes, maxillary hypertrophy, dental malocclusion [5]. In addition, changes in physical form in adolescents with thalassemia are clearly visible, such as dark skin color, paleness, thinning hair, and enlarged abdomen [12]. This impact can cause psychosocial problems and decrease the quality of life of adolescents with thalassemia. The results showed that adolescents with thalassemia can experience psychosocial disorders such as decreased quality of life (HRQOL = 79.50) [4]. While the quality of life assessment through PedsQL, SDQ, and CDI showed that there was a significant relationship between depression, anxiety, quality of life, and behavioral screening between thalassemia major adolescents and healthy adolescents [13]–[16]. The quality of life of adolescents with thalassemia can cause stress and anxiety in adolescents. In addition, a decreased quality of life will also cause a decrease in interpersonal relationships and self-esteem, and lead to depression [17].

Nurses have a role in dealing with psychological problems in adolescents with thalassemia. One of his roles as a counselor is to help accept teenagers with thalassemia who are different from other teenagers. The results showed that 80% of children with thalassemia major had at least one psychiatric disorder [7]. Nurses need to know the psychological condition of adolescents with thalassemia so that they can do prevention by providing counseling from the start [18]. Therefore, the authors are interested in conducting a literature review on the psychosocial problems of adolescents with thalassemia major. This review aims to explore the psychosocial problems faced by adolescents with thalassemia. Psychological conditions are known to be considered in providing holistic nursing care so that psychological problems can be prevented as an effort to improve the quality of life and psychological health of adolescents with thalassemia.

2. Methods and Equipment

2.1. Design

This literature review uses a design scoping review design. The reason the author uses the scoping review design is because using this methodological technique can explore new topics in the present [19]. The research framework has a broad concept to explain various relevant findings according to the research objectives [20]. The 5 core stages of the framework in this review are identification of research questions, identification of relevant study findings, study selection, data mapping, compilation of results, and reporting of analyzed study results [21].

2.2. Search methods

The databases used in the article search are CINAHL, Pubmed, and Scopus. The keywords used are: "psychosocial problems OR psychosocial" AND "thalassemia major OR thalassemia" AND "adolescent OR adolescence OR young adult". The research questions are: What are the psychosocial problems that occur in adolescents with thalassemia major?

2.3. Inclusion and exclusion criteria

The data search method in this study used PRISMA Extension for Scoping Reviews (PRISMA-ScR) to identify various topics that discussed psychosocial problems in adolescents with thalassemia major (Figure 1). Articles were selected based on inclusion and exclusion criteria. The inclusion criteria for this study were that the patient was a teenager with thalassemia, used English, was open access full text, and was set in the last 10 years (2013-2022).

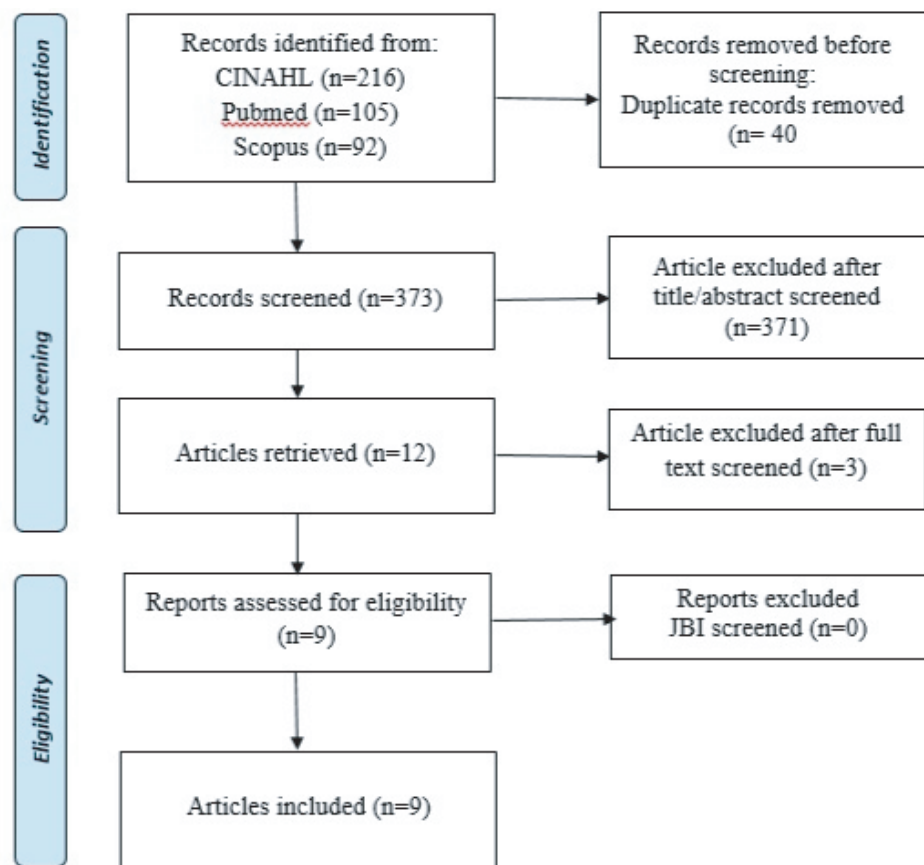


Figure 1: PRISMA Flow Diagram.

2.4. Data extraction

Articles were extracted manually using a table containing author, outcome, year, country, study design, sample, scale, and research results.

2.5. Data analysis

The articles obtained were then read in full and then analyzed comprehensively by the author. After being analyzed, psychosocial problems that occur in adolescents with thalassemia are classified according to psychosocial functions. Furthermore, each problem is described according to the disorder of psychosocial function.

3. Results

The number of articles obtained from the search is 413 articles. After duplicating the collected articles, 373 articles were obtained. Furthermore, after the elimination based on the inclusion criteria, there were 42 articles left. Then after checking the title and abstract, 12 articles were found. Then after full text screening, 9 articles were obtained for analysis.

There are 9 articles that describe psychosocial problems in adolescents with thalassemia major. The research subjects of the articles analyzed were teenagers. Of the 9 articles analyzed, there are four psychosocial disorders that occur in adolescents with thalassemia, namely disturbances in physical, emotional, social, and school functions. Researchers identified the four psychosocial function disorders by providing an explanation of what problems occur in adolescents. The results of the analysis of the article are presented in tabular form as follows:

There are 6 questionnaires used in this study, namely the Pediatric Symptom Checklist (PSCL), Pediatric Quality of Life Inventory (PedsQL), transfusion-dependent QoL (TranQoL), Strengths and Difficulties Questionnaires (SDQ), State and Trait Anxiety, and Children's Depression Inventory (CDI) (Table 3). In addition to using a questionnaire, the study also used interviews to determine the psychosocial impact experienced by adolescents with thalassemia major.

There are four types of psychosocial problems in adolescents with thalassemia major:

3.1. Physical function

Adolescents with thalassemia major often experience difficulties and limitations in carrying out activities. Difficulty in activities causes adolescents with thalassemia major to be unable to carry out activities at school and the need for caregivers [24] to assist

TABLE 1: characteristics of included studies.

Author & Year	Outcome	Country	Design	Sample	Scale	Result
[22]	Psychosocial burden and the adaptive functioning	Egypt	case-control study	100 children	Pediatric Symptom Checklist (PSCL)	Impaired adaptive function, communication, social life, and hope in adolescents with thalassemia major
[23]	Quality of life, physical, emotional, social, school, and psychosocial	Malaysia	case-control study	81 adolescents	Pediatric Quality of Life Inventory (PedsQL)	Problems that occur in adolescents with thalassemia major are physical, emotional, social, and school problems. Teenagers also lose hope for healing their illness
[24]	Physical, emotional, hope, and sympathetic pain	Lebanon	A qualitative phenomenological methodology	12 adolescents	-	There are disturbances in physical, emotional, hope, personal life, and social life functions in adolescents with thalassemia major
[25]	Hope, quality of life, and social relationship	Pakistan	observational analytical study	200 adolescents	Transfusion-dependent QoL (TranQoL)	Problems that arise in adolescents with thalassemia major are impaired school and career functions, and decreased hope
[26]	growth and development, fatigue, weakness, hope, and pain	Indonesia	qualitative study	7 adolescents	-	In adolescents with thalassemia major there are growth and development disorders, fatigue and weakness, pain, psychological, emotional aspects, anxiety and sadness, loss of hope, and frustration
[10]	Quality of life, strength and difficulties, anxiety, hope, and depression.	Iran	Case-Control Study	60 adolescents	Pediatric Quality of Life (PedsQoL), strengths and difficulties (SDQ), State and Trate Anxiety, and Children's Depression Inventory (CDI).	The problems found in adolescents with thalassemia major are psychological problems and quality of life, strength and difficulty questionnaires, hope, anxiety, and depression
[27]	body image, social life, anxiety, and isolation	Pakistan	case-control study	91 adolescents	questions is demographic information and psychosocial life aspect of affected thalassemia major patients	Problems that occur in adolescents with thalassemia major are problems with education, social life, body image, family adjustment, anxiety, hope, and isolation

adolescents in activities [23]. Based on the results of interviews, physical problems that arise in adolescents with thalassemia major are impaired growth and development,

TABLE 2: (Continued).

Author & Year	Outcome	Country	Design	Sample	Scale	Result
[28]	quality of life, psychosocial, hope, and school functioning	Thailand	cross-sectional study	64 adolescents	Pediatric Quality of Life Inventory 4.0 Scales (PedsQL 4.0)	There are disturbances in psychosocial and school functions, as well as decreased expectations in adolescents with thalassemia major
[29]	Psychosocial problems, burden, social activities, hope, and social support	China	A Cross sectional study	200 adolescents	The questions is about psychosocial burden of thalassemia	Problems in adolescents with thalassemia major are educational problems, social life problems, and decreased expectations for life due to the disease

fatigue and weakness, and pain [26]. As a result of the adolescent’s body being weak and easily fatigued, this causes adolescents with thalassemia to be hampered in participating in extracurricular activities at school [29]. Therefore they are given restrictions in terms of activities so that their body condition can be stable. In addition, adolescents with thalassemia major also feel insecure with the difficulty of increasing height, skin that turns black, and changes that occur. On the facial bones, so that this can interfere with body image [24], [27].

3.2. Emotional function

Due to the limitation of physical activity in adolescents with thalassemia major causes adolescents to be frustrated because they cannot do activities with their friends. This causes developmental disorders in adolescents [23]. Disorders that occur cause psychological and emotional problems that occur causing anxiety, decreased self-esteem, and even depression which can have an impact on decreasing the quality of life and psychological well-being of thalassemia major adolescents [22]. Based on the results of the interview, other psychological problems that arise are the emergence of emotional burden, anxiety and sadness about the future, and frustration because they feel different from others [10]. As a result of the differences between adolescents with thalassemia and other adolescents, this causes bullying in schools which makes the psychological problems of adolescents with thalassemia increase [26]. Adolescent girls with thalassemia have higher psychological problems than boys with thalassemia.

3.3. Social function

The existence of physical limitations in adolescents with thalassemia causes a decrease in social relations with their environment. So that adolescents with thalassemia are isolated from their peers and the people around them [25]. The social boundaries between adolescents with thalassemia and their friends cause the communication skills of adolescents to decline. In addition, due to bullying, adolescents with thalassemia cause them to be afraid to start communicating and make friends with friends around them [28]. Adolescents with thalassemia also admit that they receive less attention from their parents, their illness burdens their parents, and their illness limits their social life [27].

3.4. School function

Adolescents with thalassemia require monthly blood transfusions at the hospital, besides that they also experience weakness and feel tired easily [28]. This causes adolescents with thalassemia not to participate in learning activities at school [10]. This has an impact on low academic achievement, which can make adolescents have great emotional demands.

4. Discussion

Psychosocial is a condition that occurs in individuals who includes psychological or psychological aspects and social aspects, where the two aspects are interconnected with each other [5]. Psychosocial is the experience and behavior of individual humans as influenced or caused by social situations. These experiences and behaviors are influenced by social situations where these social situations occur due to interactions between individuals and other individuals [30]. Thalassemia major causes psychosocial disorders in adolescents and will affect their quality of life.

Based on the results of the study, psychosocial disorders include decreased physical, emotional, social, and school functions. Psychosocial reactions of adolescents with thalassemia show low self-esteem and psychological disorders. In addition, there are disorders of self-development, self-confidence in the future because of the disease he is suffering from. Developmental disorders that arise cause the quality of life of

adolescents to decrease. This is in line with the results of research showing that adolescents with thalassemia experience a decreased quality of life with a total HRQOL of 79.50 and lower in adolescent girls (75.29) [31]. Other studies also showed that the quality of life of adolescents with thalassemia decreased which included lower physical, emotional, social, and school functions than healthy adolescents, especially in the psychosocial domain and school function ($p < 0.001$) [32].

From 9 research articles, it was stated that the cause of psychosocial problems were symptoms of thalassemia disease and the length of treatment that caused physical and psychological problems. This stems from the appearance of symptoms of the disease, treatment that lasts a lifetime, and the pessimism possessed by adolescents with thalassemia due to differences with their peers [33]. One opinion states that adolescents with thalassemia cause a decrease in social function due to adolescents often being absent to get blood transfusions every month at the hospital [34], [35]. The results of previous studies have also shown that thalassemic adolescents also experience feelings of shame or rejection, uncertainty about disease outcomes and fear of stigmatization or death [7], [36], [37].

Psychosocial problems in adolescents with thalassemia require good support from health workers, families, and also the school environment. One study stated that adolescents with thalassemia major need additional psychological support to reduce stress, strengthen competence, and adherence to therapy for daily life. In addition, additional learning is also needed so that adolescents with thalassemia do not fall behind in learning when they have to do blood transfusions. Peer group support is also needed so that adolescents with thalassemia have a supportive environment to meet developmental stages and prevent adolescent psychosocial problems.

5. Conclusion

Based on the results of the literature review, there were 9 articles analyzed regarding psychosocial problems that occur in adolescents with thalassemia. These psychosocial problems are classified into four functional disorders, namely physical, emotional, social, and school functions. Problems that occur in adolescents cause disturbances at the stage of development so that it has an impact on almost all psychosocial aspects. Disorders of psychosocial function can occur due to individual factors, disease, and treatment of thalassemia major.

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Conflict of Interest

The authors have no conflict of interest to declare.

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TABLE 3: Questionnaires.

Questionnaire	Assessed Aspect											
	Physical function	Emotional function	Social function	School function	Spiritual function	Role function in society	Family function	Career	Psychosocial morbidity rate	Strengths and difficulties	Anxiety	Depression
Pediatric Symptom Checklist (PSCl)	x	x	x	x	x	x	x	x	√	x	x	x
Pediatric Quality of Life Inventory (PedsQL)	√	√	√	√	√	√	x	x	x	x	x	x
transfusion-dependent QoL (TranQoL)	x	x	x	√	x	x	√	√	x	x	x	x
strengths and difficulties questionnaires (SDQ)	x	x	x	x	x	x	x	x	x	√	x	x
State and Trait Anxiety	x	x	x	x	x	x	x	x	x	x	√	
Children's Depression Inventory (CDI)	x	x	x	x	x	x	x	x	x	x	x	√