

*Original Article***The effect of family-centered empowerment model on quality of life of school-aged children with thalassemia major**

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**Abstract**

**BACKGROUND:** Chronic nature of thalassemia causes changes in different aspects of life in patients, including their quality of life. Because of the important role of family in caring for children with thalassemia, this study was done to evaluate the effect of family-centered empowerment model on quality of life of the children aged 6-12 years with thalassemia in Kerman Thalassemia Center.

**METHODS:** The present experimental study was carried out on 86 thalassemic children aged 6-12 years who were randomly divided into case and control groups. Data collection tools consisted of demographic and general quality of life questionnaires in children that included physical, emotional and social aspects in addition to school functions. The questionnaires were used after determination of content validity and reliability by internal correlation method. This model was performed in test group according to four steps (threat perception, problem solving, educational participation and evaluation). Quality of life was measured 1.5 months after the intervention.

**RESULTS:** The results showed that the average quality of life of thalassemic children before the intervention was 26.23 in test group and 27.62 in the control group and they were not significantly different ( $p > 0.05$ ). However after performing the model, the average quality of life in the test group reached 35.19 while it was 28.02 in control group and the observed difference was statistically significant ( $p < 0.05$ ).

**CONCLUSIONS:** According to the impact of this model on quality of life in thalassemic children, it is recommended that evaluating the effectiveness of this model should be considered in further studies of other ages and other chronic diseases.

**KEY WORDS:** Children, empowerment, quality of life, thalassemia.

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**T**halassemia syndrome is a hemoglobinopathy which is as gene mutation in  $\alpha$  or  $\beta$  chain. If both  $\beta$  genes of the individual are abnormal, he/she would suffer from  $\beta$  thalassemia.<sup>1</sup> It has the highest prevalence in Mediterranean, tropical regions and regions near the equator latitude in Africa and Asia continents.<sup>2</sup> It is estimated that there are almost 20000 thalassemic individuals in Iran and nearly 1600 people are added to it annually.<sup>3</sup> It has the highest prevalence in northern and southern provinces of

Iran.<sup>4</sup> Thus, this disease is more prevalent in Persian Gulf, Oman Sea and the Caspian Sea which include Khuzestan, Fars, Bushehr, Hormozgan, Sistan-Baluchestan and Kerman provinces.<sup>3</sup>

Repeated, long and unpleasant treatments in thalassemia cause this disease cover all aspects of the individuals' life. It has severe and considerable consequences on general and mental health and quality of life of the patients and their families.<sup>5</sup> Diagnosis of the disease and adjusting it to a family is considered as a crisis and families react different responses. Most of the

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families can successfully adopt themselves with chronic disease of the children. In contrast, some of them also may not be successful in coping with it due to lack of access to accurate information about the disease, lack of appropriate support resources, high treatment costs, mental status and social damages.<sup>6</sup>

With regard to many achievements in treatments and reduction in mortality caused by thalassemia as well as increase in life expectancy in these patients, quality of life of the thalassemic patients is considered as one of the major indicators of the health care.<sup>7</sup> During the past twenty years, interest for evaluating and improving quality of life of the patients with chronic diseases has significantly increased and improving daily performance and quality of life of the patients with chronic diseases has become an objective.<sup>8</sup> Chronic diseases would impact on entire functions of the child and this indicates an increase in the need of child and his/her family for some measures to achieve adjustment.<sup>7</sup>

Thalassemic children and adolescents, in comparison with patients who would have short-term injuries, have more depressive symptoms and lower quality of life, and these findings would emphasize the need to be supported mentally and need of psychiatric and rehabilitation programs with aim of increasing motivation and quality of life in thalassemic adolescents. The evidences indicated that mean of anxiety, depression, aggression and shyness is higher in thalassemic patients than healthy children.<sup>9</sup> Moreover, another study indicated that anxiety and depression were in 47% of the patients and this brought about problems in their self-care and quality of life.<sup>10</sup> Accordingly, one of the main objectives of treatment is to strengthen quality of life through reducing the effects of the disease. Health team members can at least reduce the effects of the disease on their quality of life through review and assessment of the quality of life the patients.<sup>11</sup> Among the health team members, because the nurses have the closest relationship with patients and their families, they would be able to use appropriate methods and cause promotion in the quality of life and finally improve life of these patients.<sup>12</sup>

On the other hand, family which plays the main role in ensuring health and welfare of the children can have a significant impact on their quality of life. That is why nowadays attention to health-care services has changed from traditional child-centered to family-centered<sup>13</sup> one. So that it is believed that parents should participate in all the decision-makings and health-care measures for the in-hospital and out-hospital child.<sup>14</sup>

Studied researchers on health promotion have indicated that in disease prevention and treatment processes, the family-centered role would be essential. Studies have shown that most of the families are willing to participate in all the care aspects of their hospitalized child and most of them describe this participation beneficial for themselves and their child.<sup>15</sup> However, the requirement of family participation in child care is that they need to have the necessary capabilities about the disease field, various aspects of treatment and care. By empowerment, we meant helping the family so that they can be able to change.<sup>16</sup> Nursing measures which are used for empowerment should be in line with creating participation of the nurse and family with emphasis on reducing the risk factors and improving health. The nurse's method for the family should be positive, and emphasizes more on capacities than problems and deficiencies. The aim of an empowering method is to establish participation between nurse and family through responsibility and cooperation.<sup>17</sup> The family-centered empowerment model, as an Iranian Model, was provided in 2007 by Heydari et al in order to prevent iron deficiency anemia in adolescent girls with chronic iron deficiency anemia which included empowerment of the sick child and his/her family in order for coping with effects and side effects of disease and having a better control to achieve a life with a much better quality.<sup>11</sup> In the order that individuals in the families are empowered, they need to know and understand their deficiencies and have enough power to change their situations, and this ability would be obtained through gaining information, support and life skills. Family-centered intervention approach is one of approaches that

recently has attracted attention of the specialists. It integrates family-centered services with educational planning to engage family members in education and implementation.<sup>11</sup> This model is done in three phases. In the first phase (pre-intervention phase), study tools should be completed by the subjects of each group. Thereafter, the obtained data should be analyzed and needs assessment should be performed. The second phase would be the intervention phase i.e. family-based empowerment model is implemented according to mentioned steps and stages in the model during 3-5 sessions as group discussion for the child and 3-5 sessions as group discussion for the parents. These sessions hold based on existing steps in the model which consisted of perception of the threat (first step), problem solving (second step), educational participation (third step), and assessment (fourth step). Assessments consisted of two parts, assessments in each session to evaluate the previous session, and final assessment or the third phase (post-intervention phase) 1.5 months after the intervention to determine the effectiveness of the model in the two groups by completing the tools again.

Further studies also were conducted about reviewing the effect of this model. Allahyari et al showed that after implementing the family-centered empowerment model, there was a significant difference in quality of life of the children with thalassemia in Tehran, Iran in the test group comparing to the control group.<sup>18</sup> Furthermore, other studies which were conducted to study the effectiveness of this model in other diseases also indicated similar results. In a study by Teimori, the effect of family-centered empowerment model on quality of life of school-aged children with asthma was shown to cause improvement.<sup>12</sup>

Considering that this model is an indigenous model and was provided based on conditions of health services and culture of Iranian patients, the effectiveness of this model is limited in different aspects of care and accordingly, the present study designed with aim of reviewing the effect of "family-centered" empowerment model on quality of life of the children aged 6-12 years with thalassemia major.

## Methods

This was a clinical trial study which was performed to evaluate the effect of family-centered empowerment model on quality of life of the 86 children aged 6-12 years with thalassemia major who referred to Kerman Thalassemia Center in spring 2010. In this study, the subjects were divided into case and control groups according to the days they were referred to Specials Diseases Center. The children who participated in this study had referred to thalassemia center along with their parents and also had a file in this center and also expressed their willingness and readiness to participate in the study. Data collection tools included a demographic data questionnaire and pediatric quality of life questionnaire 4th ed. This questionnaire was an assessment tool for general quality of life of the children aged 6-12 years and consisted of 23 questions in four domains of physical performance (8 questions), emotional performance (5 questions), social performance (5 questions) and school performance (5 questions).

The validity of the questionnaire was evaluated and its reliability also was assessed by Cronbach's alpha. Thus, the questionnaire was translated and given to 10 faculty members and pediatricians. Necessary modifications and revising were done according to the provided comments and suggestions. To determine reliability of the provided questionnaire, it also was given to 20 subjects and after answering, reliability rate of the questionnaire was assessed using internal consistency (obtained Cronbach's alpha = 0.78). After determining the reliability and validity, in the pretest phase, the questionnaire was given to the study subjects and was compared in the two groups. No significant difference was seen in both groups in the domains of quality of life and according to the responses, their capacity requirements were identified. The next phase (intervention phase) was performed according to needs assessment; intervention included implementing family-centered empowerment model which had been designed for the intervention group. The first part in conducting this model was threat perception, increasing knowledge and awareness in association with the disease. In addition to implement

group sessions and even face-to-face training, educational pamphlets also were applied to help parents' and children's learning. The sessions were done according to needs assessment and were performed as 3-5 sessions of group discussion for the children with their parents. The place of sessions was chosen to be in the ward according to consultation with matron of thalassemia ward and relevant professors, and also in order to comfort patients. The sessions were hold for the children every time the children of the intervention group referred to special diseases center to receive care.

After increasing the awareness and knowledge of the child and the family about the disease, the second part (problem solving) was planned to increase participation in order to increase self-esteem and self-efficacy of the individual in coping with problems. In the third part, the provided presentations in the previous sessions were given to the child and his/her parents as CD so that they could participate in care giving. Last part consisted of assessments which were done in two forms. An assessment at the end of each session to determine learning rate and participation of the individuals and an assessment also which was done finally, i.e. 1.5 months after implementing the model, two groups were asked to re-complete the questionnaire. The obtained data were analyzed using Software SPSS (version 15) and descriptive sta-

tistics (mean, standard deviation etc.), and inferential statistics such as independent t-student, paired t and chi-square tests were implemented according to the objectives of the study. The average values were presented as mean (standard deviation).

## Results

Out of 68 children with thalassemia major who participated in the study, 22 were males (51.2%) and 21 were females (48.8%). Mean age of the subjects was 10.05 (1.89) years in the case group and 9.56 (2.1) years in control group ,with no significant difference. In general, chi-square test indicated that there was no significant difference between the case and control groups in variables related to demographic information ( $p > 0.05$ ).

Table 1 illustrated the comparison of various dimensions of quality of life between the two groups before and after implementing the family-centered empowerment model based on independent t-student test. According to the obtained results; it was shown that the two groups had no significant difference with each other before implementing the intervention ( $p > 0.05$ ). However, after the intervention, there was a significant difference in level of the quality of life in both groups ( $p < 0.05$ ) and there were significant differences between the two groups in all aspects after the intervention.

**Table 1.** Quality of life's dimensions in the study subjects before and after the intervention in both groups

dimensions	Before the intervention		p (t)*	After the intervention		p (t)*	Difference before and after the intervention		p (t)*
	Intervention	Control		Intervention	Control		Intervention	Control	
Physical	7.11 (2.53)	7.48 (2.10)	0.462 (0.499)	10.37 (1.77)	7.88 (2.15)	<0.001 (0.035)	3.25 (2.10)	0.39 (0.54)	<0.001 (33.00)
Emotional	5.67 (1.93)	5.76 (1.93)	0.824 (0.018)	8.58 (1.33)	5.77 (1.85)	<0.001 (1.46)	2.90 (1.77)	0.00 (0.37)	<0.001 (55.21)
Social	6.09 (1.74)	6.02 (1.81)	0.856 (0.088)	6.98 (1.56)	6.05 (1.83)	0.013 (0.581)	0.88 (0.95)	0.02 (0.26)	<0.001 (56.58)
School	7.34 (2.73)	8.34 (2.11)	0.061 (0.941)	9.26 (1.73)	8.33 (2.10)	0.028 (0.001)	2.00 (1.48)	- 0.02 (0.26)	<0.001 (57.91)
Total	26.23 (6.33)	27.63 (4.73)	0.250 (0.506)	35.19 (3.69)	28.02 (4.71)	<0.001 (0.010)	9.04 (3.97)	0.39 (0.72)	<0.001 (36.07)

Values are presented as Mean (SD); \* based on Independent t-student test



Table 2 shows the mean in each group before and after the intervention based on paired t-test. There was a significant difference in the case group in level of the quality of life of the children in all dimensions after implementing the model ( $p < 0.05$ ). In the control group, there was a significant difference in general and physical dimension after implementing the intervention; however, it was not significant in other dimensions. General and physical dimension in the control group was lower than case group. With regard to matching two groups before the intervention, it can be said that this difference could be due to effect of implementing the empowerment model in the case group.

## Discussion

The present study evaluated the effect of implementation of family-centered empowerment model on four dimensions of quality of life (physical, emotional, social and school performance) of the children with thalassemia.

In this study, it was indicated that school-aged children with thalassemia had lower quality of life in physical dimensions. Such a finding might be due to difficulties followed by the thalassemia. These patients usually suffer from many physical symptoms and side effects. Cheraghi in a study found that daily activity of most of children with thalassemia declined and rate of physical complaints in these children was more than healthy children<sup>19</sup>. Other researches also showed that children with thalassemia could not obtain an ap-

propriate score in physical dimension of quality of life.<sup>20</sup> Thus, the necessity of addressing physical needs in these children is determined more than ever and training and attention to these patients also should be done even in small communities.

One of the other findings of the study was poor quality of life of children in emotional domain before implementing the family-centered empowerment model. This finding probably was due to the issues such as difference in their appearance compared to peers, being frequently referred to the hospital, tiredness resulted from prolonged treatments and also disease's side effects that affect patients mentally and emotionally. In a study it was indicated that the most effective problems of treatment follow-up related to mental problems such as fatigue caused by treatment prolongation, hopelessness toward future, lack of confidence to do treatment affairs and lack of will to continue the treatment. In addition, it was shown that psychological problems were of higher importance than social and economic problems in treatment follow-up.<sup>21</sup> In another study by Pakbaz et al, almost half of the patients with thalassemia major had problems in self-care due to psychological problems and this caused reduction in their quality of life.<sup>10</sup> There was a significant difference in the control group in general and physical dimensions before and after the intervention. This difference most likely was due to the information through other sources; so that children in the

**Table 2.** Various dimensions of quality of life in each group before and after the intervention

dimensions	Intervention Group			Control Group		
	Before the intervention	After the intervention	p (t)*	Before the intervention	After the intervention	p (t)*
Physical	7.12 (2.53)	10.37 (1.77)	<0.001 (-9.11)	7.49 (2.10)	7.88 (2.15)	<0.001(-1.43)
Emotional	5.67 (1.93)	8.58 (1.33)	<0.001 (-10.80)	5.77 (1.93)	5.77 (1.85)	1.00 (0.00)
Social	6.09 (1.74)	6.98 (1.56)	<0.001 (-6.45)	6.02 (1.81)	6.05 (1.83)	0.32 (-1.00)
School	7.35 (2.73)	9.35 (1.93)	<0.001 (-7.81)	8.35 (2.11)	8.33 (2.10)	0.57 (0.57)
Total	26.23 (6.32)	35.28 (3.97)	<0.001 (-11.85)	27.63 (4.73)	28.02 (4.71)	0.01 (-0.53)

Values are presented as Mean (SD); \* Based on Paired t-test

control group benefited from it during the study and it improved their quality of life in general and physical dimensions.

Findings of the present study showed that after implementing the family-centered empowerment model, quality of life of children in all dimensions significantly differed from baseline values in both test and control groups. This difference was toward increasing quality of life of children in all the aspects in the test group and this reflected the need and interest of the children and their families to participate and learn in care. Similar studies also have shown that there was a significant difference in domains of quality of life of thalassaemic children in the test group comparing to the control group after implementing the family-centered empowerment model.<sup>18</sup> Other studies showed the beneficial effect of the model on quality of life of patients who suffered from other chronic diseases. In a study by Teimori in school-aged children with asthma, implementation of this model improved quality of life of these patients in all domains.<sup>12</sup>

In the present study, improvement in scores of social and school domains after the intervention was obvious in both test and control groups. In a study by Allahyari et al, it was indicated that quality of life of these patients had a significant difference with the control group in social domain after the training; however, such a difference was not mentioned in school domain.<sup>18</sup> In Nashkemit's perspective, these patients should be supported and consulted so that they can cope with their social problems.<sup>22</sup> Education can cause learning in the learner, and learning is a process to achieve knowledge and skill. It would improve the ability of the individual in health decision-making and consequently would cause changes in the behavior.<sup>17</sup> In a

study by Hasanpour Dehkordi et al, it was stated that increasing parents' awareness caused increase in longevity and quality of life of the patients with thalassemia major.<sup>23</sup>

Therefore, planning to improve mental health level of these patients is necessary. Participation in social activities, providing necessary consultations in psychological and educational fields, training the adaptive strategies along with providing new clinical and therapeutic services to the patients as well as their families who directly are engaged with these patients can increase quality of life of these patients in emotional, social and school dimensions.

### **Conclusion**

According to the findings of this study, it was indicated that quality of life of children with thalassemia was in a low level. This indicates the importance of education and participation of the patients and their families in healthcare affair. With regard to low quality of life of these patients, implementing a model to improve their quality of life seems necessary. Family-centered empowerment model, due to participation of the families in education and learning and taking care of their sick children, would be an appropriate model for further researches.

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