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Relation between Children's Well-Being and Family Function in Children with Thalassemia Major in Isfahan in 2013

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Abstract

The function of every family has a significant impact on the health of its members. Thalassemia is a chronic disease and, as the most common genetic disorder in the world, affects different aspects of life, including emotional well-being. The purpose of this study was to determine the relationship between well-being in children with a Thalassemia major and the function of their families, in Isfahan, Iran, in 2013. This was a cross sectional study and census sampling was used to collect the data. The study sample consisted of 97 children with thalassemia at the age of 10-16 years who referred to the clinic of Imam Reza, Seyed-al-Shohada Hospital in Isfahan. The subjects were evaluated using the Adolescent Psychological Wellbeing Scale and Family Functioning Questionnaire. Data were analyzed using SPSS software. The Pearson correlation coefficient showed that there was a reverse relationship between the overall score of family functioning and illness score of children with thalassemia ($r=-0.377$, $P<0.001$). In other words, children with thalassemia who are in families with a higher functionality have a greater sense of well-being. Among the 15 aspects of family functioning, the aspect of expressiveness and Lack of independence had the highest correlation with well-being in children with thalassemia. However, the aspect of locus of control and Disengagement had the lowest correlation with their well-being. The results of this study showed that there is a direct relationship between family functioning and emotional well-being of children with thalassemia major. Therefore, an important task of public health nurses is to improve the function of families in various aspects. The strengthening of family planning and implementation of projects in this regard is also necessary.

Keywords: children, thalassemia, well-being, family function

1. Introduction

Thalassemia is a group of genetic disorders caused due to a defect in the production of specific hemoglobin chains, and its most common form is thalassemia major (McKinney, Murray, James, & Nelson, 2012). Beta thalassemia major on average occurs in 1 of 4 children of parents who are both heterozygous carriers of the thalassemia trait-β (Hoffbrand & Moss, 2011). Thalassemia is the most common genetic disorder in the world and has affected about 200 million people in the world. In thalassemia, depending on whether the building chain is α or β inadequate, it is called α-thalassemia or β-thalassemia (Shayganfar, 2009). Thus far, this disease has been reported in 60 countries and is more common in the Mediterranean, parts of North and West Africa, the Middle East, the Indian Peninsula, South of the Far East, and Southeast Asia. These areas are also known as the thalassemia belt (Azizi, 2010). Today, a significant percentage of thalassemia patients in Iran are teenagers and youth. According to the statistical reports obtained from the Imam Hossein Medical Clinic in Isfahan, 1030 patients with thalassemia major referred to this center for treatment in 2011. Moreover, 700 people referred for blood transfusions and 16% of them included children of 10 to 16 years of age.

The nature and the particular treatment of this chronic disease imposes a heavy psychosocial burden on patients with thalassemia and their families (Kurian, 2010). Serious illness of a family member can cause significant

stress at any stage of life of the family. Similar to personal development, a family can be separated or return to its previous level of function. Emotional and physical health of children and their cognitive and social functioning are significantly influenced by the function of their families (Wong, Hockenberry, Wilson, Winkelstein, & Schwartz, 2002). Each member of the family experiences the effects related to the special needs of the children. Experiences of the family members and their reactions towards the children's disease directly affect each other (Kyle, 2008). Parents and families are aware of the disabling nature of the disease. Its chronic treatment is a permanent reminder that they are "different from others" and this makes it impossible for them to lead a normal life (Caocci et al., 2012).

Clearly, the health of a child is related to the health and well-being of his/her parents and their lifestyle. Therefore, a synergy exists between the family members and their health status. Family is an important source of support for people with chronic disease. Mothers of children with chronic disease have reported higher levels of stress, anxiety, depression, and feelings of isolation than mothers of healthy children (Gardner, 1919). As long as the family is taking care of their chronic patient at home, they require social and professional support to prevent a decline in their physical and emotional health (Pordanjani, Zare, Pedram, & Pakbaz, 2009). However, a chronic disease may strengthen family unity and conformity. Researchers reported that some parents of children with chronic disease felt that the illness functioned as a unifying force and it increased the sensitivity of the family members towards each other (Kurian, 2010).

One of the responsibilities of community health nurses is performing research and intervention on children's sense of well-being. In addition, the family is the smallest unit of society that community health nurses are in connection with. Community health nurses, as evaluators, trainers, guides, and referrers, are able to communicate with families and can take effective measures to improve the level of their function and the health-related needs of family members. Therefore, this study aimed to examine the relationship between emotional well-being and family functioning, and thus, to take a small step towards understanding the phenomenon of family functioning and children's sense of well-being.

Due to the importance of the family as a source of support for people suffering from chronic disease the purpose of this study was to determine the relationship between well-being in children with a Thalassemia major and the function of their families, in Isfahan, Iran, in 2013.

2. Methods

This was a cross sectional study, since it examined the relationship between emotional well-being of children with thalassemia major and the function of their families. It was conducted on families with children with thalassemia major who referred to Imam Reza Clinic of Seyed-al-Shohada Hospital in Isfahan, Iran. Inclusion criteria for the families and children were as follow: being willing to participate in the study, having a child diagnosed with thalassemia major, aged 10-16 years, referring to Imam Reza Clinic of Seyed-al-Shohada Hospital for blood transfusion, having the ability to respond to questions (not having mental retardation), lack of specific physical and mental diseases, no other diseases in addition to thalassemia. Because of the limited number of patients with thalassemia in the desired age range, census sampling was used. Finally, data were collected from 97 patients (families) who referred to Imam Reza Clinic of Seyed-al-Shohada Hospital. The simple random sampling method was used to determine the sample size. The desired population was studied using the Adolescent Psychological Wellbeing Scale and Family Functioning Questionnaire.

2.1 Adolescent Psychological Wellbeing Scale

This questionnaire was made in 1978 by Birleson, and was studied using the different aspects of the child's life and child's feelings about them (Birleson, 1981). This questionnaire was designed to determine the likelihood of depression in children and teenagers. This questionnaire includes 18 questions, each of which are associated with a different aspect of the life of a teenager and show her/his feelings towards it. The questions are answered based on "often", "sometimes", or "never".

Each question was scored 0, 1, or 2 points. Responses were scored based on the nature of the question and response. A score of 0 demonstrated that the response showed no concern, 1 the possibility of existence of concern, and 2 dissatisfaction regarding the considered topic or low self-esteem.

To determine its reliability, internal consistency was used. Cronbach's alpha was used to assess the internal consistency of the questionnaire. Internal consistency, through calculation of Cronbach's alpha of this tool, was estimated at 0.94. For localization and assessment of the face and content validity of the questionnaire, the questionnaire was given to 10 faculty members of Islamic Azad University, Khorasgan Branch, and Isfahan University of Medical Sciences, Iran. It was approved in terms of content and its proportionality to culture and

physical, mental, and social status of children in Iran, and the suitability of the questions in terms of the study objectives.

2.2 Family Functioning Questionnaire

This scale was developed and prepared by Bloom et al. (Bloom, 1985). In 1985 to evaluate the function of the system within the family. This questionnaire consists of 75 questions and descriptive statements about family characteristics. Bloom had classified them during factor analysis in 15 areas which were independently significant. These dimensions included solidarity, expression of emotions, conflicts, cultural activities and trends, entertainment trends, religious attitudes, organization, socialization, locus of control, idealization, dissociation, tolerance, lack of boundaries, dictatorship, and lack of independence. Scores ranged between 1 and 5. After analysis of the questionnaire, the function of families based on total score, were classified into 3 groups of unfavorable (75-174), relatively favorable (175-274), and favorable (275-375).

Content validity of the Family Functioning Questionnaire was approved by a group of family experts and consultants. The reliability coefficient of this questionnaire, using Cronbach's alpha, was calculated at 87% in the study by Karami et al. (KARAMI, SHAREFI, & BESHLIDEHALI, 2010) and 91% in this study.

2.3 Ethical Considerations

Since applying ethical principles in each stage of research is of great importance, in performing the present study, the researcher applied the ethical principles listed below (McKinney et al., 2012). An introduction letter was obtained from the Islamic Azad University, Khorasgan Branch, and was presented to Isfahan University of Medical Sciences (Hoffbrand & Moss, 2011). The study goals were thoroughly explained to authorities of the hospitals and a written permission was obtained and presented to the thalassemia ward of Seyed-al-Shohada Hospital, Isfahan (Shayganfar, 2009). Patients' families were free to decide whether to participate in the study or not, and families willingness to participate in the study was implemented by stating, in the context of the Family Functioning Questionnaire, that the completion of the questionnaire was voluntary.

2.4 Data Analysis

In the present study, descriptive analytical statistics were used in data analysis and its results were presented as frequency and percentage tables. Moreover, data obtained from the questionnaires were analyzed using SPSS software (version 20, SPSS Inc., Chicago, IL, USA). Kolmogorov-Smirnov test was used to determine the correlation between individual variables and sense of well-being, and family functioning. The distribution of all variables was normal. Thus, parametric statistical tests were used.

For the evaluation of the correlation between different levels of family functioning, as independent variable, and children's sense of well-being status, as dependent variable, chi-square test was used.

Furthermore, the Pearson correlation coefficient was used for the investigation of the correlation between the family functioning score in different dimensions and children's sense of well-being score.

3. Results

In this study, according to its general purpose, first family functioning was assessed, and then, the well-being of children, and finally, the relationship between the two was studies and the obtained results are illustrated in tables 1-3. Table 1 shows family function with respect to Bloom's family functioning aspects and the mean score of the subjects. As shown, the highest mean score was in the religious aspect (22.24±2.70) and the lowest mean score was in the tolerance aspect (15.05±1.90). Table 2 presents the families' functions in three levels of undesirable, relatively desirable, and desirable. Table 2 shows the frequency distribution of the level of function of families with children with thalassemia. As can be observed, no family was placed in the first category (undesirable). In addition, 45.4% of the families were placed in the second category (relatively desirable) and 54.6% of the families were placed in the desirable category. Table 3 illustrates the emotional well-being of 10-16 year-old children with thalassemia who participated in the study. This table indicates that 64.9% of the children with thalassemia had a sense of well-being without any problems, and 35.1% of them had some problems regarding their sense of well-being. Regarding the sense of well-being, the score of the children ranged between 0 and 36. The mean score of well-being of children with thalassemia was 24.77±5.55. Table 4 shows the relationship between family functioning and the sense of well-being of the children. According to the results of this table, in families with relatively desirable function, 47.7% of children with thalassemia were without any problems regarding the sense of well-being. However, in families with desirable function, 79.2% of children with thalassemia were without any problems regarding the sense of well-being. Chi-square test showed a significant relationship between sense of well-being and family functioning ($P<0.001$). Table 5 presents the relationship between family functioning and sense of well-being of children. As this table shows, there was a

direct relationship between the overall function of the family and the score of well-being of children with thalassemia (r=0.377, P<0.001). The Pearson correlation coefficient showed that there was a reverse relationship between the overall function score of the family and the lack of well-being in children with thalassemia (r=-0.377, P<0.001). In other words, children with thalassemia who are in families with better function have a greater sense of well-being. In addition, among the 15 dimensions of family functioning, expressiveness and cohesion had the highest Lack of independence and the locus of control and Disengagement had the lowest correlation with sense of well-being of children with thalassemia.

Table 1. The mean scores of family function in different dimensions

	Mean±SD
Cohesion	19.52±3.45
Conflicts	18.27±3.22
Expressiveness	18.78±3.39
Cultural activities	16.41±3.11
Active-recreational orientation	17.25±3.74
Religious	22.24±2.70
Organization	20.22±3.17
Family socialization	20.16±3.06
Locus of control	18.50±3.11
Idealization	16.74±3.07
Disengagement	16.58±2.31
Democracy	15.05±1.90
Laissez-faire family style	16.91±2.69
Authoritarian family style	17.82±2.58
Lack of independence	18.03±3.07
Overall family function	272.55±25.50

Table 2. Frequency distribution of Function levels of families with 10 to 16 year-old children with thalassemia

Family	Number	Percentage	Concentration
Undesirable (75-174)	0	0	0
Relatively desirable (175-274)	44	45.4	45.4
Desirable (275-375)	53	54.6	54.6
Total	97	100	100

Table 3. Absolute and relative frequency distribution of families regarding the sense of well-being of children with thalassemia

	Number	Percentage	Concentration
Without problem	63	64.9	64.9
With problem	34	35.1	35.1
Total	97	100	100

Table 4. Correlation between different levels of family functioning and emotional well-being of children

Function	Without problem (number/percentage)	Problematic well-being (number/percentage)	Total (number/percentage)
Relatively desirable	21/47.7	23/52.3	44/100
Desirable	42/79.2	11/20.8	53/100
Total	63/64.9	34/35.1	97/100

Table 5. Pearson Correlation coefficients between the score of family functioning in different dimensions and the score of well-being of children with thalassemia

Function dimensions	Score of well-being	
	r	P
Overall function	0.377	< 0.001
Cohesion	0.413	< 0.001
Conflict	0.138	< 0.001
Expressiveness	0.439	< 0.001
Cultural activities	0.109	< 0.001
Active-recreational orientation	0.206	< 0.001
Religious	0.183	< 0.001
Organization	0.298	< 0.001
Family socialization	0.298	< 0.001
Locus of control	0.062	< 0.001
Idealization	0.221	< 0.001
Disengagement	0.089	< 0.001
Democracy	0.093	< 0.001
Laissez-faire family style	0.311	< 0.001
Authoritarian family style	0.211	< 0.001
Lack of independence	0.155	< 0.001

4. Discussion

The aim of this study was to investigate the relationship between sense of well-being in children with thalassemia and the function of their families. The findings were categorized under 3 minor goals. Based on this aim, Herzer et al., (Herzer et al., 2010) in a research on family functioning in families with children with a chronic disease, concluded that their overall function was desirable. Haghighipoor (Haghighipoor, 2011) identified the family functioning of couples who referred to health centers in Isfahan. In this study, the overall function of the families was relatively desirable. The difference in the level of family functioning between the present study and the study by Haghighipoor may be attributed to the different tools used to examine family function. Marini and Stebnicki (Marini & Stebnicki, 2012) believe that the children's illness can create additional stress for other family members and impair family functioning. This opinion can be correct for other chronic diseases, but, based on the results of this study, it is not correct for children with thalassemia major.

Hadi et al. (Hadi, Karami, & Montazeri, 2009) conducted a study on health-related quality of life in patients with thalassemia major. They concluded that the patients' mean score of health-related quality of life in the physical dimension was lower than that in the control group. However, in the psychological aspect, the two groups had no significant differences. The reason for this difference may be physical complications such as tissue hypoxia that over time causes pulmonary heart disease, complications of the eye, ear, nose, throat, and joints, and neurological complications. Northam et al. (Northam, Lin, Finch, Werther, & Cameron, 2010) performed a study on psychosocial well-being and functional outcomes in patients with type I diabetes 12 years after the onset of their illness. They concluded that this group's psychosocial well-being 12 years after the onset of this chronic disease was similar to healthy people of the same age (control). This similarity can be justified by the opinion of Danner and Chan that over time the demands and expectations of patients suffering from chronic illness will become consistent with their illness. In the present study, the reason that two-thirds of 10-16 year-old children with thalassemia did not have any problems with regards to sense of well-being may be this matter. Brandow et al. (Brandow, Brousseau, Pajewski, & Panepinto, 2010) performed a study on painful event of blocked arteries in patients with cycle of tuberculosis (a chronic disease) and its effect on the well-being of children. They showed that the mean score of health-related quality of life of children at the time of the painful event was lower than 7 days after it. These results also show the acute and chronic effects of diseases on the sense of well-being. According to the results, acute disease complications decrease the sense well-being of children and create problems. Nevertheless, over time and chronically the patients adapt to the disease complications; thus, their effects on well-being decrease. Hatami and Motamed (Hatami & Motamed, 2014) examined life satisfaction of children with beta thalassemia major and healthy children in 5 areas in Southwestern Iran and focused on the

positive indicators of children's well-being. They concluded that children with thalassemia, compared to healthy people, were more satisfied with their lives. This result was consistent with the present study results.

The main objective of this study was to determine the relationship between sense of well-being of children with thalassemia major and family function in Isfahan in 2013. It was shown that there was a relationship between sense of well-being and family function ($P<0.001$). Farajzadegan et al. (Farajzadegan, Koosha, Sufi, & Keshvari, 2013) examined the relationship between family functioning and well-being of women and concluded that dysfunctional family function affects women's quality of life and well-being. Waldfogel et al. (Waldfogel, Craigie, & Brooks-Gunn, 2010) in a study on fragile families (single unmarried parent) and the child's sense of well-being, examined aggressive behavior, anxiety, and depression in children of these families. They concluded that the level of aggressive behavior, depression, and anxiety, which are indicators of well-being, was higher in children of fragile and vulnerable families compared to normal families and have a negative impact on family functioning. The results of the study did not support the relationship between family function and parents' non-standard working programs and working in different shifts. The results of the present study showed that there was a relationship between the well-being of 10 to 16 year-old children with thalassemia and their family function. Kuhlthau et al. (Magnuson & Berger, 2009) in a study concluded that family-centered care was related to the improvement of children with disabilities and chronic diseases who had special healthcare requirements. They found that family-centered care can improve the use of services, reduce dropout rates of children with chronic illness and behavior problems, and improve the functioning of the family. Since children's behavioral problems are a part of their sense of well-being, reduction of these problems increases the sense of well-being of the child. Based on the papers reviewed by Kuhlthau et al. family-centered care increases the well-being of children and improves family function. These results were consistent with the present study results. Magnuson and Berger (Magnuson & Berger, 2009) examined the relationship between family structure and well-being of children. This study examined single-parent and two-parent families and the influence of family type on their children's emotional well-being. The results showed that the two-parent family structure had a positive effect on the child's sense of well-being and children in single-parent families had more behavioral problems and their success rate was lower. An aspect of wellbeing is its psychological aspect. The two-parent family structure improved the well-being of children, reduced behavioral problems, increased family cohesion, and improved overall family functioning. Gold et al. (Gold, Treadwell, Weissman, & Vichinsky, 2011) in a study on 7 to 16 year-old siblings of patients with tuberculosis cycle, found a relationship between the function of families with a member with chronic disease and behavioral problems. This was consistent with the present study results.

5. Conclusion

In general, the analysis of the results of this study showed that there was a relationship between the well-being of children and their family's function. This relationship was significant based on the different levels of family function and its aspects. Children with thalassemia who were in families with a more desirable function in terms of function levels had a greater sense of well-being. Furthermore, children with thalassemia who obtained higher scores in terms of different aspects of family function had higher well-being scores. The results of this study can be used in providing health services for families with 10-16 year-old children with thalassemia. It can attract the attention of authorities, the Ministry of Health, and provincial health authorities to identifying well-being in children with thalassemia and their family's function. Thus, better services can be provided for these families. Since each province in Iran has a special center to interact with these children, this research can help to improve the interaction of these centers with families and children with thalassemia. They can have a more positive effect on families' function through paying more attention to the well-being of children and its relationship with family function. This research can help public health nurses understand the sense of well-being of 10-16 year-old children with thalassemia and its relation with family functioning. Therefore, they can provide better services to the families that are part of the society. It can also be beneficial for educational planners, teachers, and educators of schools of nursing, and cause them to place greater emphasis on family function in community health courses. It is hoped that this study can be a small step toward improving the lives of children with thalassemia and reducing family problems. The present study had several limitations. Limited number of participants in the study, non-random sampling, and the use of self-report method on children's well-being were points that required greater caution in concluding from the results.

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Authors' Contributions

All authors contributed to the initial design of the research. Ahmad Ebrahimi collected data. Mahrokh Keshvari was the supervisor of research and Heidarali Abedi was the advisor.

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Competing Interests Statement

The authors declare that there is no conflict of interests regarding the publication of this paper.

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