



# Exploring the Association Between Barriers to Care in Children With Thalassemia Major and Their Parents' Perceptions of Primary Care and Quality of Life in Kerman in 2015

Leila Vali<sup>1</sup>; Maryam Seyednezhad<sup>2\*</sup>; Zahra Farahmandinia<sup>3</sup>; Moghadameh Mirzai<sup>4</sup>; Zhale Abdi<sup>5</sup>

<sup>1</sup>Research & Technology Deputy, Environmental Health Engineering Research Center, Kerman University of Medical Sciences, Kerman, Iran

<sup>2</sup>Department of Health Management and Economics, School of Public Health, Tehran University of Medical Sciences, Tehran, Iran

<sup>3</sup>Department of Pediatrics, School of Medical, Kerman University of Medical Sciences, Kerman, Iran

<sup>4</sup>Department of Biostatistics and Epidemiology, School of Health, Kerman University of Medical sciences, Kerman, Iran

<sup>5</sup>National Institute of Health Research, Tehran University of Medical Sciences

## Abstract

**Background and Objectives:** The aim of this study was to explore the relationship between barriers to care with parents' perceptions of primary care and quality of life in children with thalassemia major in Kerman, Iran.

**Methods:** A cross-sectional study was conducted in 2015. The sample included 150 children aged 6 to 15 years with thalassemia major and one of their parents. Data were collected using 3 standardized questionnaires: barriers to care questionnaire (BCQ), parents' perceptions of primary care (P3C), and the pediatric health related quality of life (PedsQL). To determine the association between demographic characteristics and barriers to care t test and ANOVA were used. Correlation coefficient was used to determine the relationship between barriers to care and parents perceptions of primary care and health-related quality of life.

**Results:** The mean (SD) of BCQ was  $63.93 \pm 9.08$  (out of 100), and the mean (SD) for parents' perceptions of primary care (P3C) was  $51.12 \pm 17.98$  (out of 100). The mean score of health-related quality of life (PedsQL) reported by the children and their parents were  $41.01 \pm 22.38$  and  $40.63 \pm 21.04$ , respectively. Perceived barriers to care was significantly associated with parents' perceptions of primary care ( $P < 0.0001$ ), health-related quality of life reported by children ( $P = 0.021$ ) and parent-reported of quality of life ( $P = 0.020$ ).

**Conclusion:** This study provided important information for policy makers, managers, doctors, nurses and other health care team members and may help them to develop and implement effective interventions to support children with chronic diseases and their families.

**Keywords:** Barriers to care, Thalassemia major, Parent perceptions, Quality of life, Children

## Background and Objectives

To achieve equity, health systems must ensure all population have access to quality health services. One of the fundamental goals of health policy makers around the world is to facilitate access to health services so that all segments of society can benefit from health services properly.<sup>1</sup>

Nowadays, chronic diseases are the major cause of health problems in developed countries. Chronic diseases occur in all age and socioeconomic groups. It is anticipated that by 2050, 167 million people will be diagnosed with chronic diseases all over the world.

According to data from the National Research Council of America, 18%-15% of children and adolescents have a chronic health condition and the prevalence of the chronic diseases almost has doubled over the past 2 decades. One of the chronic diseases threatening children's health is beta-thalassemia. The World Health Organization (WHO) has announced thalassemia as the most common chronic genetic disorder among 60 countries which annually affects the lives of about 100000 children.<sup>2</sup> Thalassemia is the most common genetic disorder which affects 22000 Iranians.<sup>3</sup> Although thalassemia has been reported from more than 60 countries, countries with most prevalence of the disorder are located in the belt of malarious, including the Mediterranean, parts of West and North Africa, the Middle East, the Indian subcontinent and South East Asia, which Iran is amongst them.<sup>4</sup>

Despite the efforts made by healthcare workers, many

\*Corresponding Author: Maryam Seyednezhad, 1Tehran University of Medical Sciences, Tehran, Iran. Email: maryam.seyednezhad@gmail.com

people do not receive timely, appropriate and quality health services. Vulnerable children to poor outcomes due to poverty, race/ethnicity, lack of health insurance and low education level of parents are more likely to be underdiagnosed and have not access to appropriate care. These people usually receive lower quality of health care, have lower satisfaction and have to be hospitalized.<sup>5</sup> “Socio-behavioral” barriers to care prohibit families from productive interaction with healthcare system and reduce the likelihood of access to timely care and consequently positive impacts.<sup>6</sup> Parents faced barriers while seeking care for their children such as long waiting time, transportation, rude staff and lack of language concordant staff that prevent them from receiving high-quality care.<sup>7</sup> Seid and colleagues proposed a conceptual model to understand how vulnerable children’s access to health care system, their experience of the health care system and their result outcomes.<sup>6</sup> According to this model, the barriers to care is a multi-dimensional construct including pragmatic, skills, expectations, feeling ignore, knowledge and beliefs. Based on the model, a number of modifiable factors can be addressed to enhance health outcomes for vulnerable children including having potential access to health care systems, using high quality primary care, and adhere to providers’ advice. However, barriers to care can distort the relationship between these factors and as a result, may have negative effects on the ultimate goal, which is enhancing the quality of life in vulnerable children.<sup>8</sup>

## Methods

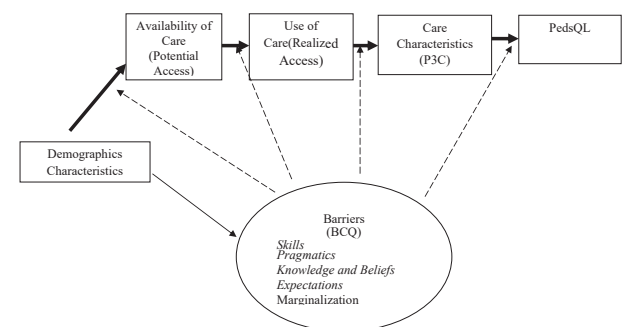
This is a cross-sectional study conducted from June to September 2015. The sample included 150 children with thalassemia major in the age group 6-15 years along with one of their parents who referred to the Samen al-Hujaj center in Kerman, Iran. Available sampling was used until the desired sample number was achieved. Exclusion criteria included lack of willingness to cooperate and incomplete filling in the questionnaire.

This study conducted based on the model developed by Seid et al<sup>8</sup> in 2004 to measure barriers to care in children with chronic diseases. According to this model, to improve vulnerable children’s health outcomes, children and their families must have potential access to health care system, use care appropriately, receive care that is interpersonally and technically of high quality, and adhere to providers’ recommendations. However, barriers to care that are influenced by demographic characteristics and social conditions of their families can distort the relationship between these factors and as a result, the ultimate goal of increasing the quality of life in vulnerable children

with special health care needs. In the present study, the demographic characteristics of parents and children came first, then the potential and actual access to health services was measured. Potential access was measured through parents’ report of whether their child has a health insurance? and whether their child has a personal doctor or nurse? Realized access was assessed by parents’ report of forgone care by these questions: During the past 6 months did you have difficulty for receiving care for your child that you or your doctor believed to be necessary? And, in the past 12 months, was there any time that you thought your child should receive medical care, but you received no care? Ultimately, 3 questionnaires of barriers to access to care (BCQ), understanding parents of primary care (P3C) and health related quality of life (PedsQL) were applied to collect data (Figure 1).

The BCQ has been designed to measure parents’ experience of circumstances that may interfere with accessing or using care, with making the most of the clinical encounter, or with complying with medical instructions. Mean scores are calculated based on a 5-point Likert scale for each item and transformed to a 0-100 scale (never=0, almost never=25, sometimes=50, 75=very often and almost always=100). Higher scores indicate fewer barriers. The questionnaire consisted of 39 questions in 5 dimensions. Cronbach alpha, a measure used to assess the reliability, has been reported 95% for BCQ.<sup>8</sup>

High-quality pediatric care is the key to improve health outcomes, control health care costs and improve access to care. For this purpose, a questionnaire assessing the parents’ perceptions of their experiences with their children primary care (P3C) was applied. The P3C contains 23 questions in 6 dimensions. Using a Likert scale, the items were scored 0-100 (never=0, almost never=25, sometimes=50, 75=very often and almost always=100). Higher scores indicate better primary care. The reliability



**Figure 1.** A Conceptual Model of How Barriers to Care Can Affect Health Care Quality and Health-Related Quality of Life for Vulnerable Children.

of the questionnaire using Cronbach's alpha was 95%.<sup>9</sup>

The Pediatric Quality of Life Inventory (PedsQL) was applied to measure health-related quality of life from the perspective of children and their parents. The questionnaire contains 23 questions in 4 dimensions. Using a Likert scale, the items were scored 0-100 (never=100, 75=almost never, sometimes=50, most of the time=25 and almost always=0), so that a score of 100 was considered as the best quality of life. Cronbach alphas were 0.88 and 0.9 for parent proxy report and child-self report questionnaires.<sup>10</sup> Questionnaires were separately and independently completed by children and their parents.

The original questionnaires were translated into Farsi by the authors, and then was translated back into English by a bilingual translator (English-Farsi) who was blind to the original text. Given that the questionnaires used for the first time in Iran, content validity was used and the questionnaires were confirmed by the relevant experts (5 pediatrics). To determine the test-retest reliability, the questionnaires were completed on 2 occasions with a 10-day interval by 30 randomly selected people (15 children with thalassemia and their parents). Cronbach alphas for BCQ, P3C, and PedsQL (children and parents) were 83%, 88%, 84% and 88%, respectively.

Questionnaires were distributed among children and their parents. To determine the association between demographic characteristics and barriers to care ANOVA and *t* test were used. To determine the association between parents' perceptions of barriers to primary care and health-related quality of life, the correlation coefficient was used. Continuous variable were described using

frequency, mean, and standard error. Data were analyzed using SPSS version 19.  $P < 0.05$  was considered to be statistically significant.

## Results

The mean age of the patients was  $11.61 \pm 2.77$ . In total, 54.7% of the patients were boys and the rest were girls. Approximately, 63% of the families lived in urban areas. Most of the families have one child with thalassemia major (77.3%) and the rest had 2 children with thalassemia major. Thirty eight percent of fathers had a low education level and 9.3% of them had higher education. Among mothers, 36.7% had a low education level and 9.3% had higher education.

Investigating potential access to services showed that 86.7% of children had health insurance and only 9.3% of them have a regular doctor. To express realized access, 33.3% of the parents stated that during the past 12 months there were times that their child was in need of medical care, but for whatever reason they did not receive it. Thirty-two percent of parents stated that during past 6 months there were times they experienced difficulties to get necessary care for their child.

As seen in Table 1, parents reported fewer knowledge and beliefs barriers ( $78.04 \pm 23.48$ ) and more pragmatic barriers ( $50.53 \pm 12.56$ ). In general, the mean score for the BCQ was ( $63.9 \pm 39.08$ ).

Table 2 shows that in P3C questionnaire, communication was scored the highest ( $65.58 \pm 25.93$ ) and the longitudinal continuity was scored the lowest ( $29.48 \pm 40.41$  by parents). Overall, the average score of parents' satisfaction with primary care was ( $51.12 \pm 17.98$ ).

Children self-reported quality of life was poor ( $41.01 \pm 22.38$ ). Social functioning yielded the highest score ( $46.86 \pm 23.67$ ) and school functioning yielded the lowest score ( $36.16 \pm 27.83$ ) (Table 3).

Parents reported poor health-related quality of their children life ( $40.63 \pm 21.04$ ). Looking at the differences at the scale level, social functioning scored highest of all PedsQL subscales ( $47.33 \pm 24.17$ ) and school functioning scored lowest of all PedsQL subscales ( $25.59 \pm 33.93$ ) (Table 4).

There was a significant relationship between barriers to care and perceived access to pediatric primary care by parents ( $P < 0.01$ ), which means by increasing the number of barriers to care, parents reported difficulty getting pediatric primary care. The relationship between average score of barriers to care with contextual knowledge ( $P < 0.01$ ), communication ( $P < 0.01$ ), comprehensiveness ( $P = 0.008$ ) and coordination ( $P = 0.007$ ) were significant, which means that by increasing the number of perceived

**Table 1.** Parent-Reported Barriers to Care

Scales	Mean (SD)	Min	Max
Pragmatics	50.53±12.56	25	80.56
Skills	54.33±11.49	28.13	78.13
Expectations	71.07±17.58	28.57	100
Marginalization	72.19±14.59	38.64	100
Knowledge and beliefs	78.04±23.48	6.25	100
Total	63.93±9.08	40.33	83.13

**Table 2.** Parents' Perceptions of Primary Care

Scales	Mean (SD)	Min	Max
Longitudinal continuity	40.41±29.48	0	100
Access	45.25±21.7	0	100
Contextual knowledge	56.33±25.15	0	100
Communication	65.58±25.93	0	100
Comprehensiveness	49.73±24.3	0	100
Coordination	44.41±25.45	0	100
Total	51.12±17.98	0	97.83

barriers to care, parents reported poor contextual knowledge, communication, comprehensiveness and coordination (Table 5).

There were significant relationships between the barriers to care and health-related quality of life reported both by children ( $P=0.021$ ) and their parents ( $P=0.020$ ), which mean the more barriers to care were reported, the worse quality of life was perceived by both children and their parents (Table 6).

## Discussion

In the present study, barriers to care from the perspective of parents of children with thalassemia major were studied. Mean scores for BCQ was  $63.9 \pm 39.08$ . At the subscale level, parents reported fewer knowledge and beliefs barriers ( $78.04 \pm 23.48$ ) and more pragmatic barriers ( $50.53 \pm 12.56$ ).

In Seid et al study the mean score of barriers to care from the perspective of parents was ( $86.32 \pm 14.09$ ). Similar to the present study, parents reported fewer knowledge and belief barriers ( $91.03 \pm 17.11$ ) and more pragmatic barriers ( $78.32 \pm 18.39$ ).<sup>6</sup> In another study

conducted by Seid and colleagues, the mean score of barriers to care from the perspective of parents was ( $78.35 \pm 15.15$ ). In their study, parents experienced fewer knowledge and beliefs barriers ( $80.97 \pm 18.44$ ) and more pragmatic barriers ( $74.67 \pm 19.34$ ).<sup>8</sup>

Flores et al studied barriers to health care for children in Latin American countries. They reported transportation problems, lack of ability to pay, long waiting time, no health insurance and lack of cultural understanding by employees as the most important barriers encountered by parents while seeking care for their children.<sup>11</sup> These results are consistent with the present study's results. Parents of children with thalassemia had a lot of problems in terms of pragmatic measures including waiting time for appointments, difficulty getting care on holidays and problems related to costs. However, in Seid et al study, the mean score of barriers to care was much higher than present study, which means parents faced fewer problems in receiving health services. Given that the barriers examined in this study mostly were social-behavioral, such difference was expected. Since these studies conducted in 2 different contexts (i.e. Seid et al study conducted in a developed country, the United States, and our study conducted in a developing country, Iran), it can be concluded that the way people and healthcare workers communicate are different in the 2 countries. In the current study more financial problems were reported by parents than Seid et al study, because the United States is amongst the countries with a high spending per capita on health care.

The perceptions of parents to primary health care in children with thalassemia major were further assessed in the present study. The level of satisfaction with primary care among parents was at a medium level ( $51.12 \pm 17.97$ ), in which communications scored the highest ( $65.58 \pm 25.93$ ) and longitudinal continuity scored ( $40.41 \pm 29.48$ ) the lowest.

Chukwu et al conducted a similar study to investigate parents' perceptions of the quality of primary care services on 111 people. Total score of perceived quality of primary care for children was 65%, which was lower as compared to the

**Table 3.** Quality of Life Perceived by Children With Thalassemia Major

Scales	Mean (SD)	Min	Max
Physical functioning	37.41 ± 26.02	0	100
Emotional functioning	45.76 ± 27.56	0	100
Social functioning	46.86 ± 23.67	0	100
School functioning	36.16 ± 27.83	0	100

**Table 4.** Quality of Life Perceived by Parents of Children With Thalassemia Major

Scales	Mean (SD)	Min	Max
Physical functioning	37.7 ± 25.11	0	100
Emotional functioning	45.33 ± 26.32	0	100
Social functioning	47.33 ± 24.17	0	100
School functioning	33.93 ± 25.59	0	100
Total	40.63 ± 21.04	0	100

**Table 5.** Association Between Barriers to Care and Quality of Primary Care

P3C Scales	BCQ Scales					
	Total	Pragmatics	Skills	Expectations	Marginalization	Knowledge and Beliefs
Total	0.318**	-0.245**	0.444**	-0.572**	0.180*	0.005
Longitudinal continuity	0.043	-0.209*	0.294**	0.282**	-0.043	-0.169*
Access	0.039	-0.001	0.125	0.159	-0.033	-0.124
Contextual knowledge	0.286**	-0.160	0.364**	0.476**	0.148	0.051
Communication	0.465**	-0.169*	0.423**	0.554**	0.364**	0.197*
Comprehensiveness	0.215**	-0.272**	0.368**	0.482**	0.094	-0.013
Coordination	0.220**	-0.220**	0.297**	0.421**	0.154	-0.011

\*Significant at  $P < 0.01$

\*\*Significant at  $P < 0.05$

**Table 6.** Association Between Barriers to Care and Parent-Reported Quality of Life/Children-Reported Quality of Life

PedsQL	BCQ Scales					
	Total	Pragmatics	Skills	Expectations	Marginalization	Knowledge and beliefs
PedsQL total score patient self-report	-0.188*	-0.355**	0.025	0.149	0.139-	-0.266**
PedsQL total score parent proxy report	-0.190*	-0.355*	-0.004	-0.167*	-0.123	-0.294**

\*Significant at  $P < .01$ \*\*Significant at  $P < .05$ 

expected grade (80%). Communication received the highest score (79%), while the lowest score (39%) belonged to the comprehensiveness of care.<sup>12</sup>

Seid and Varni performed a study to measure the quality of primary care for children. Overall, mean score of their perceptions of primary care was reported ( $67.41 \pm 22.29$ ). Among subscales, the communication scored the highest ( $82.75 \pm 25.63$ ) and the longitudinal continuity scored the lowest ( $57 \pm 25.68$ ), respectively.<sup>13</sup> Seid et al studied the impact of race/ ethnicity and language on the access to primary care for children on a sample of 3406 of parents. The reported quality of primary care was different according to race/ ethnicity. Asian (57.5) and Latin Americans parents (54.3) reported lower scores as compared to African Americans (62.3) and whites (60.2). In this study, parents in all groups scored communication the highest and longitudinal continuity the lowest.<sup>14</sup> Consistent to our study, parents faced fewer communication barriers and more barriers for longitudinal continuity in above mentioned studies. However, in these studies, parents were more satisfied in all aspects of primary care compared to the current study, which could be due to 2 different health systems of Iran and the United States as well as the cultural differences.

In the present study health-related quality of life in children with thalassemia major were studied from the perspective of both patients and parents. Parent-reported PedsQL ( $21.04 \pm 40.63$ ) was lower than self-reported PedsQL of children ( $22.38 \pm 41.01$ ). In both children and parents reported quality of life, the highest and lowest scores belonged to social functioning and school functioning subscales, respectively.

Khaledi et al showed that parent-reported quality of life of children with asthma ( $81.43 \pm 21.73$ ) was poorer than children's-reported quality of life ( $59.96 \pm 12.77$ ).<sup>15</sup> Ismail et al. conducted a study on 96 children suffering from thalassemia major and 235 healthy children. They concluded that the quality of life in children with thalassemia was significantly lower ( $68.91 \pm 12.12$ ) than their healthy counterparts ( $79.79 \pm 11.60$ ).<sup>16</sup> Valizadeh and colleagues compared the quality of life in children with cancer reported by themselves and their parents. They showed that the parent-reported quality of life (mothers & fathers:  $55.93 \pm 8.60$  &  $56.84 \pm 9.25$ ) was lower than children-reported quality of life ( $67.19 \pm 14.61$ ).<sup>17</sup>

A study showed that parent-reported and children-reported

quality of life was different in children with hemophilia across emotional and social dimensions, with a poor quality perceived by parents.<sup>15</sup> Alavi and colleagues compared perspective of children with thalassemia and their parents about the quality of life of these children. There was no significant difference between perceived quality life of children and their parents in 2 subscales of social and school functioning. However, significant differences were seen between the 2 groups in emotional and physical subscales.<sup>3</sup>

Similar to results of previous studies, the results of current study indicate that chronic diseases such as thalassemia disease can affect children daily lives and normal activities. Besides physical consequences, emotional dimensions of chronic diseases, which are often overlooked, can have negative effects on patients and their family.

The present study examined further the relationship between barriers to care and parents' perceptions of primary care. High quality primary care is an important determinant of outcomes in vulnerable children with chronic medical conditions. The relationship between parents' perceptions and barriers to primary care was statistically significant ( $<0.01$ ), which means that by increasing the number of barriers to care, parents reported a low level of satisfaction with primary care in all subscales. The relationship between the dimensions of perceived barriers to care with some of subscales defining their perceptions of primary care such as parents contextual knowledge ( $<0.01$ ), communication ( $<0.01$ ), comprehensiveness ( $P=0.008$ ) and coordination ( $P=0.007$ ) were significant, which indicates that by increasing the number of barriers to care, parents reported poorer contextual knowledge, weaker communication, and lack of comprehensiveness and coordination.

Seid and colleagues aimed to determine the psychometric properties of BCQ among parents of children with asthma. They found that the relationship between barriers to care and the overall satisfaction of parents with primary care was significant ( $<0.001$ ).<sup>6</sup>

The relationship between barriers to care with access, contextual knowledge, communication,

comprehensiveness and coordination was significant ( $<0.001$ ).<sup>6</sup> Seid and colleagues conducted another study on barriers to care among children with chronic diseases. In this study, the relationship between the barriers to care and parents perceptions of primary care was found significant ( $<0.01$ ). The relationship between barriers to care and longitudinal continuity ( $<0.05$ ) access, contextual knowledge, communication, comprehensiveness and coordination were also significant ( $<0.01$ ).<sup>8</sup>

One of the goals of the current study was to determine the relationship between children health-related barriers to care and quality of life in children with thalassemia major. The relationship between barriers to care and parent-proxy health-related quality of life of children with thalassemia was significant ( $P=0.021$ ). The relationship between barriers to care and children self-reported quality of life was significant as well ( $P=0.020$ ). The results indicate that the higher the number of barriers to care perceived by parents and children, the worse quality of life was reported by them.

Seid and colleagues conducted a study to examine the psychometric properties of BCQ among parents of children with asthma. In this study, the relationships between the barriers to care and parent-proxy health-related quality of life ( $P<0.001$ ) and self-reported health-related quality of life in children ( $P<0.01$ ) were found significant.<sup>6</sup> Seid and colleagues conducted another study to investigate barriers to care in children with chronic diseases and reported a significant association between barriers to care and health-related quality of life ( $P<0.01$ ).<sup>8</sup>

According to the model, if children with chronic diseases have access to health services and high-quality primary care, their quality of life may improve. However, the relationship is not that straightforward. Barriers to care could affect parents' perceptions of primary care and consequently the quality of life. Barriers to care identified in this study, mostly were behavioral barriers that emerged from parents' socio-economic conditions. It is expected that parents with a better socio-economic situation, face fewer barriers, experience better access, receive high quality primary care and therefore report higher quality of life for their children. Since most parents participated in this study were among low-income families, demographic characteristics did not have significant impact on barriers to care. Because thalassemia major is known as a specific disease, all of them had access to essential health services such as blood transfusion therapy and therefore, primary care did not have a significant relationship with access to care. However, since they received primary health care from different centers, the association between barriers to care and parents perceptions of primary care was found

significant. Further, those who faced more barriers, had more problems receiving primary care, received lower quality of care and consequently had lower quality of life.

## Conclusion

The quality of life in children with thalassemia could be enhanced through a better understanding of the barriers faced by parents of such children and designing evidenced-based interventions to target modifiable factors including, reducing the waiting time, improving communication between medical teams and families, respecting families beliefs, providing adequate information about the disease, considering individual and family needs, as well as improving primary care for these children.

## Abbreviations

Barriers to Care Questionnaire (BCQ), parents' perceptions of primary care (P3C), and the pediatric health related quality of life (PedsQL)

## Competing Interests

The authors declare no competing interests.

## Authors' Contributions

LV Contributed substantially to the conception and design of the study, analysis and interpretation. ZF is a specialist of the blood diseases and working as the director of the clinic. She participated in the design of the study and helped in acquisition of data. MM helped in analyzing and interpreting the data. MS collected data and drafted the first version. ZA helped in revising and writing the final draft of the manuscript.

## Acknowledgements

Authors appreciate all parents and their children that participated in the study.

## References

1. Khayatan M, Nasiri Pour AA, Amini M, Mohamad Nejad SM. The Effective factors on receivers' access to health care services in urban health care centers. *Journal of Payavard Salamat*. 2011;4(3-4):18-27. [Persian].
2. Mirhaghjou SN, Shasti S, Reza Masouleh S, Emami Sigarodi A, Atrkar Roshan Z. Study the Life Skills of 11-19 year old Children affected by Thalassemia referring to Educational and Remedial Centers in Rasht city from their Mothers' Point of View 2009-2010. *Journal of Holistic Nursing and Midwifery*. 2010;20(63):16-21. [Persian].
3. Alavi A, Parvin N, Kheiri S, Hamidi Zade S, Tahmasebi S. Comparison of perspective of children with major thalassemia and their parents about their quality of life in

- Shahrekord. Journal of Shahrekord University of Medical Sciences. 2007;8(4):35-41. [Persian].
4. Saki N, Dorgalaleh A, Kashani Khatib Z, Alizadeh S, Rahim F, Galehdari H, et al. Prevalence of Co-Inheritance of Alpha-Thalassemia with Beta-Thalassemia and Beta-Hemoglobinopathy in Ahvaz City. Journal of Ardabil University of Medical Sciences. 2013;13(3):287-96. [Persian].
  5. Seid M. Overcoming Barriers to Care for Vulnerable Children with Asthma R40 MC. <https://www.mchlibrary.org/collections/docs/R40MC08044.pdf>. Published 2008.
  6. Seid M, Opirari-Arrigan L, Gelhard LR, Varni JW, Driscoll K. Barriers to care questionnaire: reliability, validity, and responsiveness to change among parents of children with asthma. Acad Pediatr. 2009;9(2):106-13. doi: 10.1016/j.acap.2008.12.003.
  7. Crain EF, Kercksmar C, Weiss KB, Mitchell H, Lynn H. Reported difficulties in access to quality care for children with asthma in the inner city. Arch Pediatr Adolesc Med. 1998;152(4):333-9. doi: 10.1001/archpedi.152.4.333.
  8. Seid M, Sobo EJ, Gelhard LR, Varni JW. Parents' reports of barriers to care for children with special health care needs: development and validation of the barriers to care questionnaire. Ambul Pediatr. 2004;4(4):323-31. doi: 10.1367/a03-198r.1.
  9. The PedsQL™ Measurement Model. [http://www.pedsq.org/about\\_pedsq.html](http://www.pedsq.org/about_pedsq.html).
  10. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Med Care. 2001;39(8):800-12. doi: 10.1097/00005650-200108000-00006.
  11. Flores G, Abreu M, Olivar MA, Kastner B. Access barriers to health care for Latino children. Arch Pediatr Adolesc Med. 1998;152(11):1119-25. doi: 10.1001/archpedi.152.11.1119.
  12. Chukwu JM, Molloy EJ, Morgan J. Parental Perception of the Quality of Primary Care Paediatric Services. Pediatr Res. 2011;70:572. doi: 10.1038/pr.2011.797.
  13. Seid M, Varni JW. Measuring primary care for children of Latino farmworkers: reliability and validity of the parent's perceptions of primary care measure (P3C). Matern Child Health J. 2005;9(1):49-57.
  14. Seid M, Stevens GD, Varni JW. Parents' perceptions of pediatric primary care quality: effects of race/ethnicity, language, and access. Health Serv Res. 2003;38(4):1009-31.
  15. Khaledi S, Moridi G, Valiee S, Shikhzakariaei N, Omati A. Comparison view point of children and their mothers about quality of life children with Asthma. Iranian Journal of Nursing Research. 2013;8(3):65-72. [Persian].
  16. Ismail A, Campbell MJ, Ibrahim HM, Jones GL. Health Related Quality of Life in Malaysian children with thalassaemia. Health Qual Life Outcomes. 2006;4:39. doi: 10.1186/1477-7525-4-39.
  17. Valizadeh L, Hosseinpour-Feizi A, Joonbakhsh F. Comparing the quality of life in children with cancer in Tabriz Children Medical and Training Center reported by themselves and their parents, 2013. Journal of Clinical Nursing and Midwifery. 2014;3(1):1-8. [Persian].

**Please cite this article as:**

Leila Vali; Maryam Seyednezhad; Zahra Farahmandinia; Moghadameh Mirzai; Zhale Abdi . A Survey of Barriers to Health Research Promotion. International Journal of Hospital Research 2017, 6(3):x-x.