

## The Effect of Family-Centered Empowerment Model on the Mothers' Knowledge and Attitudes about Thalassemia Disorder

Kargar Najafi M MA<sup>1</sup>, Borhani F PhD<sup>2</sup>, Dortaj Rabari E PhD<sup>3</sup>, Sabzevari S MSc<sup>4</sup>

1-International graduate student units of Bam, Kerman University of Medical Sciences

2-Assistant Professor of nursing, Kerman University of Medical Sciences

3-Epidemiology PhD, Assistant Professor, Kerman University of Medical Sciences

4-Master of nursing, medical sciences Kerman University

Received: 5 April 2011

Accepted: 23 July 2011

### Abstract

#### Background

Thalassemia is one of the most common human genetic diseases in the world and it provides many problems for patients, families and health care system. This model helped the family with sick children to empower to face disease and its complications. To reach this aim, the knowledge and attitude of patients and their families about the disease should be increased. This study was aimed at determine the effectiveness of family-centered empowerment model on the mothers' knowledge and attitudes about thalassemia disorder.

#### Objective

To assess the effect of family-centered empowerment model on the mothers knowledge and attitudes about thalassemia disorder in children with thalassemia.

#### Materials and methods

This semi-experimental study was performed on 86 children with thalassemia that were randomly divided into two groups. A questionnaire was filled with demographic information and knowledge and attitude of the mothers about the disease. These questionnaires were tested for content validity and reliability (internal correlation). Information was given to first group and second group did not receive any more information. After intervention final evaluation was performed one and half month later.

#### Results

Data analysis showed that before intervention, the average awareness and attitude of the mothers in test group were no significantly different with control group ( $p>0.05$ ). However, after performing model in the test group, this averages were significantly higher in test group than control ( $p<0.05$ ).

#### Conclusions

The results of this study indicated that implementation of the family-centered empowerment model are effective on knowledge and attitudes of mothers of children with thalassemia.

#### Key words

Children Thalassemia, Empowerment, Knowledge, Attitude, Mothers

#### Corresponding Author:

Fariba borhani, Asistant Professor of nursing, Kerman University of Medical Sciences, Kerman, beginning Haft bagh Highway, Kerman University of Medical Sciences, School of Nursing and Midwifery, Tel: 09133439254  
Email: faribaborhani@msn.com

## Introduction

Thalassemia major is a chronic genetic disease and it caused by impaired synthesis of one or more of the globin polypeptide chains. This disease is the most common genetic disease in human (1). The disease has the highest prevalence in Mediterranean, tropical regions and regions near the equator on the continent of Africa and Asia. Disease in the northern and southern provinces of the country (which country) has the highest prevalence (2). In Iran, this disease in the northern and southern provinces of the country has the highest incidence. It is more common in Khuzestan, Fars, Bushehr, Hormozgan, Sistan-Baluchestan and Kerman than other areas (3). Currently, about three million people in Iran carriers defective genes, and about 25 thousand patients with thalassemia major have been identified (4). Disease such as thalassemia and other chronic debilitating diseases require long and sustained treatment (5). Catching chronic disease is affecting on interactions with the physical and social environment in which they live and can change communicate with peers and people. Sense of confidence and lack of frequent absences from school due to illness or blood transfusions, hospitalization, frequent and never understood the point they will not be without symptoms, irreparable consequences could be for them (6). Considering the impact of thalassemia on all aspects of life of children and their families, these people need proper training according to educational level, age and other factors that influence their learning (9). Public education programs have noted to inform individuals of the disease effectively and consistently communicate with health team, patients and their families (11). Today, parental education can prevent the complications or minimize them before the disease cause irreparable and dangerous problem for children (14). Family-centered empowerment model by Alhani in 2001 has provided to prevent iron deficiency in adolescent girls. Allahyari and her colleagues implemented family centered empowerment model to increase quality of life of children with thalassemia (16).

This study evaluated the effect of empowering family centered model on knowledge and attitude of mothers, who have children with thalassemia referred to Thalassemia Center of Kerman.

## Materials and Method

This study is a quasi-experimental study. Eighty six mothers of children 6 to 12 years old with thalassemia referred to Thalassemia Center of Kerman entered to this study after inform consent and explaining the plans and goals. Subjects randomly were divided into two groups, control and intervention. The knowledge and attitudes of all parents were evaluated with questionnaire before the intervention. Questionnaires included demographic information, and knowledge and attitudes of parents about thalassemia. The questionnaire was tested for content validity and reliability (internal correlation). Intervention started in one group based on steps in the model. They introduced in the group sessions and discussed the use of pamphlets and slides about the disease. According to this model the first knowledge and awareness of parents and patients about the disease was increasing. In the second step or decoding phase problem, their confidence should be increased. Then they concluded that they could participate in programs of care. In third step, educational pamphlets and other handouts and CD audio tracks were given to family members, which raise awareness about the disease and improve attitude of children in care process. Then evaluation was performed one and half month after intervention for both groups. The results of this evaluation were analyzed through statistical software SPSS version 15.

## Results

The mean age of children participating was 10.05 ( $\pm 1/89$ ) years old in testing group and 9.56 ( $\pm 2/1$ ) years old in control group. Other information obtained from the demographic questionnaire test and control groups is given (Table 1). According to the results, there were no significant difference between knowledge and attitude of patients in two groups before the implementation of the intervention ( $p > 0/05$ ) (table 2). After intervention there was significant difference in awareness and attitude in the two groups ( $p < 0/05$ ) (Table 3). The results showed that significant differences was exist in all aspects of children awareness ( $p < 0/05$ ) before and after intervention. But in the control group not significant difference was observed before and after intervention ( $p > 0/05$ ).

Table1) demographic subjects

variable	groups	control		test	
		Relative frequency	Absolute frequency	Relative frequency	Absolute frequency
Father age (years)	<40	11/6	5	18/6	8
	60-41	63/8	27	46/5	20
	>61	20/9	9	27/9	12
	Died	4/7	2	7	3
Mather age (years)	<40	41/9	18	46/5	30
	60-41	58/1	25	53/5	23
father's occupation	free	62/8	27	51/2	22
	Employed	9/3	4	16/3	7
	other	27/9	12	32/6	14
mother's occupation	housewife	95/3	41	83/7	36
	employed	4/7	2	16/3	7
Relative	yes	79/1	34	81/4	35
	no	20/9	9	18/6	8
father's education level	below high school diploma	83/7	36	79/1	34
	Diploma and above	16/3	7	20/9	9
Mother's education level	below high school diploma	93	40	86	37
	Diploma and above	7	3	14	6
City of living	capital	30/2	13	30/2	13
	city	34/9	15	55/8	24
	rural	34/9	15	14	6

Tables 2) compare the mean and SD awareness and attitudes of two groups before and after intervention

Study time	Before intervention		Independent t-test	After intervention		Independent t-test
Questions	The mean (± SD)			The mean (± SD)		
groups	test	control	P value	test	control	P value
awareness	12/98 (±4/99)	12/47 (±3/87)	0/597	18/86 (±3/63)	13/16 (±3/65)	0/001
attitude	13/58 (±13/9)	11/02 (±11/26)	0/351	22/09 (±10/02)	12/13 (±10/83)	0/001

Tables 3) compare the mean and standard deviation of different dimensions of knowledge in both groups before and after intervention.

Question of awareness	groups		Paired t-test	Control group		Paired t-test
	Testing group The mean (± SD)			The mean (± SD)		
Time of intervention	Before intervention	After intervention	P value	Before intervention	after intervention	P value
Disease	5.19(±2.107)	8.43(±1.210)	0/001	4.88(±1.802)	4.56(±1.327)	0/57
Symptoms	2.00(±0.873)	2.87(±0.658)	0/001	1.84(±0.721)	1.97(±1.803)	0/08
Treatment	4.00(±1.799)	8.03(±0.127)	0/001	4.21(±1.846)	4.64(±0.610)	0/08
Detection	1.09(±1.087)	2.67(±0.803)	0/001	0.93(±0.828)	1.13(±0.107)	0/32
Transfer ways	0.70(±0.964)	2.97(±1.581)	0/001	0.60(0.821)	0.58(±2.107)	0/08

## Discussion

This study has been discussed the impact of family centered empowerment model on knowledge and attitudes of parents of children with thalassemia. Fortunately, knowledge and attitude of the parents about their children disease were significantly increased after intervention. It was explained before in Allahyari research that was done about the effect of family empower model on quality of life of children with thalassemia (18). Also Teimori et al showed that implementation of this model are improved the quality of life of school-age children with asthma (17).

Pordehkordi et al showed face to face education like lecture can have positive effects on awareness and attitudes of children parents (19). Other study in Ahvaz has been shown that setting up a counseling center could have a positive effect in improving knowledge and attitude of the parents with thalassemia children (20).

Other study evaluated knowledge, attitude and practice of minor thalassemia mothers. This study showed low parental awareness and attitudes about thalassemia introduced as the main obstacle to preventing the disease (21).

A national program of prevention of thalassemia has started in Iran 14 years ago (22) But the role of parents and family has not been considered in this program.

Preventive program about thalassemia is very important, because they use 25% of annual blood product (23). Participation of patients and families in care and treatment is very important and effective (24). This model implements participation of parents and other family members involved in child care. Heidari said that this participation has vital role in enabling members to accept disease nature and improves capacity of the health care (18). Eshghi et al studied the awareness of parents of the children with thalassemia in family planning methods (20). Also, another study has been conducted by Jafari et al who examine the effectiveness of the thalassemia prevention plan to increase awareness of the carrier couples (25).

Parent attitude toward the disease was indicated significantly different in both groups after intervention using empowerment model. Similar results were obtained in previous study, which showed attitude of parents were significantly increased after face to face training (26). Also Tochina in his study showed that parents attitudes change by face to face training, and their confidence was increased. Education had a greater impact on their attitude so face to face training is necessary to change the attitude (27).

Results showed that implementing family centered of empowerment can increase awareness and attitudes of mothers of children with thalassemia. They could deal better and easier with more awareness and better attitude.

## Acknowledgments

The authors thank all patients, their parents, and nurses in Kerman Thalassemia Center. They also thank Dr Alhani, who allowed to using her model.

## Conflict Of Interest

None

## References

1. Khani H, Majdi M, Azad marzabadi E, Montazeri A, Ghorbani A, Ramezani M. Quality of life in Iranian Beta-thalassemia major patients of southern coastwise of the Caspian Sea. 2009; 2(4): 325-332
- 2- Vichinsky EP, MacKlin EA, Waye JS, Lorey F, Olivieri NF. Changes in the epidemiology of thalassemia in North America: a new minority disease. Pediatrics 2005; 116(6): 818-25
3. Rrabani A, Azar keyvan A, Farhadi M, Korosedri GH. Clinical Evaluation of 413 Thalassemia Patients. Tehran University Medical Journal. 2000; 3: 35-42
4. Abdolsamadi H, Torkzaban P, Hoseini M. Parotid saliva of chemical compounds, the rate of dental caries and gingivitis in thalassemia major. Journal of Dentistry Shiraz University of Medical Sciences 2008; 8(4): 76-81
5. Pakbaz Z, Treadwell M, Yamashita R, Quiyolo K, Foote D, Quill L, et al. Quality of life in patients with thalassemia intermedia compared to thalassemid major. New York: Academy of Sciences 2005: 457-61
6. Alavi A, Parvin N, Kheyri S, Hamidizade S, Tahmasebi S. Comparison of perspective of children with major thalassemia and their parents about their quality of life in Shahrekord. Shahrekord University of Medical Sciences Journal. 2007; 8(4): 35-41
7. Tabarsi B, Marbaghi A, Safavi M, Afkhami M. Comparative survey of problems in thalassemia major patients with regular and irregular follow ups of therapeutic principles. Blood. 2007; 4(1): 33-40
- 8- Olivieri NF. Medical progress: The beta-Thalassaemia. N England J Med 1999; (8):99-109
9. Politis C, Richardson C, Yfrantopoulos J. Public knowledge of thalassemic patients. National Center of Social Research Athens, Greece 2002; 12(2):151-4
10. Tsiantis J, Dragonas T, Richardson C, Anastasopoulos D, Maserà G, Spinetta J. Psychosocial problems and adjustment of children with beta-thalassemia and their families. European Child & Adolescent Psychiatry. 1996; 5(4):193-203
- 11- Diploma A, Vullo C, Zani B, Facchini A. Psychosocial integration of adolescents and young adults with thalassemia major. New York: Academy of Sciences 1995:355-360
12. Stanhope M, Lancaster J. Community and public health nursing. 6<sup>th</sup> ed. New York: Mosby; 2004. 57-82
13. Hasanpour dehkordi A, Delaram M, Safdari F, Salehi tali SH, Hasheminia A, Kasiri K, et al. Shahrekord university of medical sciences journal. 2008; 2: 52-58
14. Atkin K, Ahmad WI. Living a normal life: young people coping with thalassemia major or sickle cell disorder. Soc Sci Med 2001; 53(5): 615-26
15. Armstrong FD. Thalassemia and learning: neurocognitive functioning in children. Ann N Y Acad Sci 2005; 1054: 283-9
16. Allah yari A, Alhani F, Kazemnejad A. The effect of family-centered empowerment model on the Quality of Life of school-age B-thalassemic children. Iranian Journal of Pediatrics. 2006; 4: 455-461
17. Teimori F. The effect of family-centered empowerment model on the quality of life of school- age children with Asthma (dissertation). Tarbiat Modares University.;2010
18. Heydari M, Alhani F, Kazemnejad A, Moezzi F. The effect of empowerment model on quality of life of Diabetic adolescents. Iran J Pediatr 2007; 17(1): 87-94
19. Pourdehkordi HA, Delaram M, Safdari F, Salehitali SH, Kasiri K, Masoudi R, Parvin N, Moulavi M. Comparison of the effects of lecture and booklet methods on awareness and attention of parents of children with thalassemia major. Shahrekord university of medical sciences journal 2008; 10(2): 52-58
20. Eshghi P, Rahimi M, Razaghi A. Evaluation of effect of family practice consultation on knowledge, attitude and practice of major beta thalassemic's parents in the prevention program in southeast of Iran. Scientific medical journal 2006;5(2): 507-514
21. Khin EH, Aung MH, Thein TM. Thalassemia in outpatient department of the Yangon Children's Hospital in Myanmar: knowledge, attitudes and practice in relation to thalassemia. Southeast Asian J Trop Med Public Health 1992; 23(2):269-72
22. Najmabadi H, Karimi-Nejad R, Sahebjam S, Pourfarzad F, Teimourian S, Sahebjam F, et al. The beta-thalassemia mutation spectrum in the Iranian population. Hemoglobin 2001; 25(3): 285-96
23. Abolghasemi H, Amid A, Zeinali S, Radfar MH, Eshghi P, Rahiminejad MS, et al. Thalassemia in Iran: epidemiology, prevention, and management. J Pediatr Hematol Oncol 2007; 29(4): 233-8

24. Valizadeh F, Ghasemi F. Medical staff attitude toward participation in the care of their hospitalized children. *Hayat* 2008; 14(1): 69-76
25. Jafari f, Nodesharifi A, Zayeri F. Effectiveness of the prevention of thalassemia plan on increasing awareness and couples and married couples withdrew in the city of Gorgan. *Journal of Gorgan medical science* 2006; 8(4):68-72
26. Ghorbani GH, Ranjbar R, Izadi M, Esfahani A. Effect of face to face training and pamphlets on AIDS knowledge and attitudes of adults. *Journal of Military Medicine* 2007; 9(1): 57-65
27. Tuchinda S, Chotpitayasunondh T, Teeraratkul A. Knowledge, attitudes, and practices of senior high school students regarding human immunodeficiency virus infection. *J Med Assoc Thai* 1998; 81(2): 130-5