Making Comparison between the Impact of Family-based Empowerment Model and Collaborative Care Model on the Quality of life among Little Children Infected with Major Thalassemia

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Making Comparison between the Impact of Family-based Empowerment Model and Collaborative Care Model on the Quality of life among Little Children Infected with Major Thalassemia

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Abstract:

Purpose: Children are regarded as the future architectures forevery society and their growth and health guarantee should be one of the major concerns for all societies.

Since thalassemic children suffer from the most problems in their life quality dimensions, this present study has brought about making comparison between the impact of Family-based Empowerment Model and Collaborative Care Model on the Quality of life among Little Children Infected with Major Thalassemia.

Materials and Methods: This present research has been implemented as clinical trial over 90 major thalassemic children who had the criterions to enter in our study. Samples were divided randomly and simply into family based tests group, collaborative care and control group (30 children for each group). Demographic questionnaires and life quality of children (peds Qol) have been completed before intervention and for the whole three groups and the family based empowerment model and collaborative care model have been implemented for test groups during 4 sessions each was 45 minutes. By the usage of statistic tests and SPSS software, the average scores for life quality has been compared in 1/5 month after intervention with information received before intervention.

Findings: Based on the acquired results, there is a meaningful statistic difference for the all life quality dimensions (physical, emotional, social and educational) and the total score for the life quality after intervention for the family based test group and for the child and parents report

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(p<0/001). There was a meaningful statistical difference for the total life quality dimensions among collaborative care test group except the social dimension and we were also witness for the existence of a meaningful statistical difference for the physical and educational function in parents report. There was also a meaningful statistical difference for the emotional, social and educational dimensions in control group and child and parents report (p<0/001).

Discussion and Conclusion: with regard to the improvement of the life quality for the major thalassemic children, it seems that the implementation of the family based empowerment model is more effective than collaborative care model, for that reason, it is suggested for the nurses working in this domain, to take advantage from this model.

Keywords: Family based Empowerment Model, Collaborative Care Model, Life Quality, Major Thallasemia

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Introduction:

Children are the future architectures for every society and all societies should be concerned about their growth and health guarantee. So that, in its statement about children rights, the United Nations Organization has encouraged all its members in order to programming for the care and children health maintenance in society (1,2).

Thalessemia is regarded as the prevalent form of a hereditary anemia throughout the world which is the result of deficiency in one of the globin chains synthesis in hemoglobin (3). There are about 270 million vectors for the major hemoglobin deficiency all over the world, based on the estimation and 300 t0 400 thousand babies born annually who are infected with several types of anemia all over the world (4). Having about 20000 thalassemic patients and 3 million vectors for this disease, Iran is one of the countries locating over the thalasemia belt in the world (5). There are 2300 thalasemic children among 2700000 people in Systan and Balouchestan Province and Zabol city also has 217 major thalasemic patients (6). One of the numerous problems of major thalasemic patiens is the overload of iron resulted from several blood injection which increase iron absorption. Overload iron sediment in tissues can result in serious damages to the vital parts of body such as heart, liver and endocrine (7).

Nowadays, thalassemia is a chronic diseases and by the help of the existing treatment methods to improve iron overload control, life expectance has been enhanced among these patients. Frequent blood injection, however, and longtime usage of iron drugs influence over other life aspects of these patients and significantly impacted the general health, psychic health and finally life quality of these patients and their families (8,5). Life quality holds an extended concept which encompasses the whole life dimensions such as health. Life quality in its terminology means how to live. Its concept, notwithstanding, is exclusive for each person and it is different among different people (9). Life quality is regarded as a basic indicator and it includes several dimensions such as physiological, functional and psychic aspects of people (10).

People comprehension about life quality will be influenced by diseases and its side effects and its treatment (11). For the thalassemic patients particularly who are frequently under the stress and pain of blood injection (12). Several studies, in this regard, have shown the low level of life quality

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among thalassemia patients in comparison with healthy people in similar age. Karakan et al, for example, proved that thalassemic patients hold a low score for all life quality dimensions (13). In another study, also, Pankto and Torchavers in Thailand were witness for the similar results about lower life quality score among thalassemic children and in comparison with control group (14). Life quality disorder among these patients overshadows their social life, family, job and their entertainments and it also increase the hospitalization and death risk resulted from this sickness (15). Through changing diseases pattern during recent years and the enhancement of chronic diseases, life quality and its relation with health has gained more attention to itself (16). So, life quality condition for these patients is the important treatment and care foundation all over the world (17). Empowerment of the major thalassemic patients can pave the way to achieve the above mentioned goal, so that, they can resist the diseases side effects and to enjoy from better life quality (18).

Diploma et al study shows that three factors of suitable treatment, preventing from body transformation and educational programs in order to inform people about this disease, effective and continuous relationship of health team with patients and their family demands special attention in order to decrease their problems (19). Education, here, plays an important role for the chronic diseases management (18).

Because of their occupational and professional responsibilities, nurses are the most suitable health team for teaching family and social workers. They also can support and care about those families with thalassemic child, so that, they can enhance their awareness and attitude improvement in different treatment and care fields (20). Nowadays we are spectator for searching to achieve more effective treatments and life quality enhancement of these patients (21). Most scholars believe in empowerment as a process which forms as the result of communication with other people and improves life quality of the people infected with chronic diseases and their families (22). One of the effective methods for chronic patients' empowerment, is to perform family based empowerment model (23). What we mean with family empowerment, is to help family to acquire change power (24, 25). Family based empowerment, attracts the social worker and the family role for making decision in order to promote health level, through a correct and powerful decision

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making, they help themselves to control their health. They can achieve their goals for health improvement by caring about themselves (26, 27).

One of the key parts of people empowerment is their collaboration process which nowadays has attracted the instructors' attention and they will use it for the promotion of their life quality (28). For this model of care and collaboration, there exists a mixture of model infrastructures which means collaboration care. Nobility and effectiveness, in the view point of this model, depends on the correct, desirable and the quality of caring relationship (29). Like the traditional approach, the collaboration care does not focus on nurse as the basic care factor, but, it concentrates on the simultaneous, interactive and balanced role of the whole effective persons existing in the care process which is the same group collaboration role (30). Even a high level and specialized care cannot result in complete positive effects without family collaboration and it will include negative results in other situations (31).

In different studies such as Allahyari et al (32), Alijanirenani et al (33) and Zinati et al (3), there is meaningful difference for the average score of life quality among test groups, before and after intervention which have acquired from the implementation of the both educational method (family based empowerment model and collaborative care model). For these studies, however, the preference of one educational method has not evaluated over other one. The researcher, based on this issues, decided to take action in order to decrease infection and mortal rate, to increase efficiency and diseases management for treatment, to enhance diseases adaptation and life quality promotion for major thalassemic patients through performing a contrastive analysis between these two educational methods and to determine the most effective method.

Material and Methods

This was a trial- clinical research which performed for two test and control group as the previous and after form. Children in age range of 12 to 17 infected with major thalassemia formed the research communities who have referred to the Special Diseases Center in Zabol city. Enjoying the minimum literacy for reading and writing, being a student, tendency for volunteer participation in study, living in Zabol or its near villages, good relationship and not participating in similar educational course simultaneous with intervention study, have been the criterions to participate in

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study. Leaving out the study demanded some factors such as patients and parents tendency to give up the study, occurrence of a special event which was effective on life quality (such as death of a close relative), suffering from a special psychic-spiritual diseases, parents are member of health team, not completing the questionnaire, incomplete participation in sessions, death or immigration of the patient, using medicines other than the routine consuming medicines for major thalassemia children. The number of estimated samples were based on the similar papers results (32), based on first type error 0/05, statistic power 0.80 and including 15 percent for samples encompassing by the usage of the statistic software of STATA version 11 (at least 30 persons for each group).

Demographic information questionnaire and life quality of children questionnaire (peds-QOL) were the data gathering tools in this research. The questionnaire for the life quality of children is a standard one to evaluate life quality of children who are under 18 years old which it,s validity and durability has been confirmed by Allahyari et al in TARBIAT MODDARES University based on test re test method with Kronbach Alpha of 0.84 (32). This questionnaire includes 23 questions in 4 domain of physical function (8 questions), emotional function (5 questions), social function (5questions), school function (5 questions) with Likert 5 Scale which are never (4), rarely (3), sometimes (2), usually (1), and always (0). The numbers of 0 to 100 will be regarded as the acquired score for each scale. The higher score means higher life quality and lower score means lower life quality. Individual information questionnaires and the questionnaires for the life quality of children or peds- (QOL) have been completed by the researcher of the research sections before intervention. In next step, 90 patients with life quality score lower than 75 have been chosen based on entrance criterions. Then, patients were categorized randomly and through lottery in to three, family based empowerment model (group A), collaborative care (group B) and control (group C). The intervention step has been performed just for the test groups (A&B) and the control group received the common cares. Fridman method has been used for the life quality analysis and the educational programming has been implemented based on the determination of educational needs of patients. The family based empowerment model and the collaborative care for the two groups A&B have been performed respectively in 4 and 45 minutes sessions during 2 weeks. The final appraisal has been implemented through second gathering of data 1/5 after intervention (30) and by completing life quality questionnaire by samples. Powerpoint, question and reply, interview and group discussion were used for presenting educational sessions. SPSS software was used for the analysis of data acquired by the statistic tests.

Findings

Age domain of research samples was 12-17 based on findings and age average and standard deviation in family based group was 14/33+-2/03, collaborative care group was13/83 +-1/91 and control group was 13/80+-1/98. Three groups were homogenous based on sexual distribution, education level, family record, the number of infected people in family, monthly blood injection frequency and consuming medicines (p>0/05).

There was a meaningful difference between life quality score of child in three study groups before and after intervention based on results of making comparison between groups. There was a meaningful statistic difference between life quality score of child before and after intervention for the intergroup comparison and for the two, family based and control group, however, the collaborative care group did not show any difference. The life quality score of child had 82/2/% statistically meaningful enhancement. The total child score for the collaborative care group faced with a statistically meaningless change of 2/1/%. For the family based group, we were witness for the more meaningful change percent in comparison with other two groups and in comparison with the collaborative care group, this percent was more for the control group (table 1).

Table 1: child life quality score changes for the intervention and control groups, before and after intervention

Total score	group	Before middle intervention (middle quarter difference)	After middle intervention (middle intervention quarter)	Changes percent (standard deviation)	Intergroup test	
					P-Value	Test type

Family based		48.9 (42.1-55.7)	84.2 (80.2-86.9)	82.2(50.1)^{a}	<0.001	Wilcoxon
Collaborative care		57.6 (48.6-67.4)	56.5 (51.1-60)	2.1(27)^{b}	0.619	Wilcoxon
control		63.6 (58.1-67.9)	48.4 (43.2-53.5)	-21.2(21)^{c}	<0.001	Wilcoxon
Intergroup test	p-value	<0.001	<0.001	<0.001	-	-
	Test type	Anova	Kruscal Wallis	Kruscal Wallis	-	-

Discussion

The family based empowerment model based on the research findings, resulted in the enhancement of life quality of children in the view point of child and in comparison with collaborative care model and the control group. Although in view point of child, there were meaningful changes for the life quality score for the both control and family based empowerment model, however, this score had not faced with any change for the collaborative care group.

It is believed that among the positive achievements of this study we can mention to discussion, dialogue and active collaboration of patient together with the active member of family, the presence of family near to the patient and the enhancement of patient power for health monitoring, increase of accepting responsibility.

Borhani et al, found that the implementation of family based empowerment model could result in the enhancement of life quality of the school age children infected with thalassemia (34). Allahyari et al, in another study proved that the implementation of family based empowerment model in test group have been meaningfully effective for the enhancement of life quality of school age children infected with thalasemisa in comparison with control group (32). Pahang et al, in their study proved that the implementation of family based empowerment model have been effective for the enhancement of life quality of kidney implant patients (35). The patients' addresses of this present study were chronic ones, because these patients demand following process implementation for

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achieving their desirable and demanded principles. Khosravan et al, proved the positive impact of family based empowerment model for the enhancement of life quality of female patients infected in stress based urinary incontinence (10). Although the dimensions investigated by Khosravan et al, includes knowledge, self-esteem and hygiene actions and it is different with dimensions studied in this paper, however, as the patient and family member simultaneously participated in this study, their awareness and knowledge have been increased and they have been effective on patients life and life quality of patients. Rajabi et al proved that the implementation of family based empowerment has been effective in different dimensions for the enhancement of life quality of children infected with asthma (36). Chen & Lee believe in the effective results of empowerment intervention for the life quality improvement of patients with chronic diseases (37). So that, it is necessary to empower patient and his/her family for the better diseases control. Farzami et al in their study, investigated about the impact of family based empowerment model over the life quality improvement of old patients infected with angina pectoris. There was a meaningful difference for the different life quality after intervention for the control and test group after intervention based on these researchers' findings (26). These findings demonstrate these truth that it is possible to promote and improve life quality of patients approximately by taking advantage from using family based empowerment model. For that reason, a family based approach for children and families and effective service providers will result in the promotion of treatment services and the increase of family satisfaction from the delivered services.

Life quality score for the collaborative care group in this study did not show any meaningful difference for before and after intervention child report. Alijanirenani et al, in their study results proved the enhancement of life quality score for children in school age that infected with major thalasemmia in child report (33) which is not consistent with this present study. In their study entitled in Determination of Collaborative Care Model Impact on the Quality of Adults Infected with Major Thalassemia, Zinati et al proved the statistical meaningful enhancement of life quality score after intervention in comparison with before intervention (3) which is in contrast with this present study. It seems that face and appearance changes among these patients, growth stop and

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delay in maturity has resulted in the decrease of their social activities and it will have negative impact on their life quality.

The control group did show a statistically meaningful difference in life quality after intervention in comparison with before intervention condition in this present study. The reason relates in the more attention of control group patients toward their treatment affairs during monthly referral for completing the research questionnaire. Zare et al, in their study for the implementation of collaborative care implementation impact on life quality of patients suffering from heart diseases after intervention in control group, proved a statistical meaningful difference which is similar to this present study.

This study brought about suitable witnesses for the effective impact of family based empowerment model in comparison with collaborative care on life quality improvement of thalassemia infected children. So, it is suggested to dedicate importance to life quality of patient and family simultaneously and to pay attention to non-medical interventions together with medical ones in treatment programming. Based on the acquired results and with regard to the increasing pace of chronic diseases and shortage of physical space in treatment domain, it is suggested to pay attention to the family based empowerment model as one of the fundamental elements in medical and nursery educational domain.

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