Journal of Caring Sciences, 2016, 5(2), 223-229
doi:10.15171/jcs.2016.024
http:// journals.tbzmed.ac.ir/ JCS

The Effects of an Orientation Program on Quality of Life of Patients with Thalassemia: a Quasi-Experimental Study

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ARTICLE INFO

Article Type:
Original Article

Article History:
Received: 25 Aug. 2015
Accepted: 29 Nov. 2015
ePublished: 1 Sep. 2016

Keywords:
Thalassemia
Quality of life
Orientation program

ABSTRACT

Introduction: Medical advances have improved life expectancy and survival of patients with thalassemia. However, as getting older, patients with thalassemia experience different complications which impair their quality of life. The aim of this study was to examine the effects of a nurse-implemented orientation program on quality of life in patients with thalassemia.

Methods: A convenience sample of 55 patients with thalassemia were recruited in this quasi-experimental study. Patients were randomly allocated to control or experimental groups. A demographic questionnaire, Thalassemia quality of life questionnaire, and 36-item short form health survey were used for data collection before and one month after the intervention. In the intervention group, 1.5-month orientation program including of the three steps of inauguration, implementation, and closure was implemented, while the control group received routine care. The Chi-square, independent t-test and paired-samples t-test were used for data analysis by using SPSS ver.13 software.

Results: The intervention and control group did not differ significantly from each other regarding demographic characteristics. Moreover, no significant difference was observed between the two groups regarding the quality of life scores after the implementation of orientation program.

Conclusion: Implementing a short-term orientation program was not effective in enhancing the quality of life in patients with thalassemia; hence, developing long-term multimodal strategies may result in better improvement.

Please cite this paper as: Rafii Z, Ahmadi F, Nourbakhsh SMK, Hajizadeh E. The effects of an orientation program on quality of life of patients with thalassemia: a quasi-experimental study. J Caring Sci 2016; 5 (3): 223-29. doi:10.15171/jcs.2016.024.

Introduction

Thalassemia is the most common hereditary hemoglobinopathy worldwide.[1] It is more common in the Mediterranean, north African, as well as east and west Asian countries such as Greece, Italy, Turkey, Thailand, Indonesia, Saudi Arabia, Pakistan, Afghanistan, and India.[2] It is also common in our country, Iran; however, the prevalence of the disease differs in different areas of Iran. Akhavan-Niaki et al., reported that the prevalence of thalassemia in the Caspian Sea and the Persian Gulf areas of Iran is more than 10% of population while it ranges from 4% to 8% in other areas of the country.[3]

Thalassemia is treated mainly by blood transfusion and iron chelation therapy.[4]

Currently, great advances have been made on the strategies for managing thalassemia and prolonging survival among afflicted patients.[5]

Nonetheless, the signs, symptoms, and complications of thalassemia still negatively affect patients and their families' physical and mental health,[6] quality of life (QOL), and their functioning.[7] Previous studies have shown that patients with thalassemia have significantly poorer QOL compared with healthy people.[8-12]

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Given the better life expectancy of patients with thalassemia due to the aforementioned advances, the challenging issues of managing long-term complications of the disease and improving afflicted patients' QOL have been raised.[13] Strömberg argued that patients with thalassemia need to learn self-care skills for improving their own QOL.[14] Moreover, studies have shown that patients with thalassemia are eager to receive self-care information and educations. Providing high-quality information to patients regarding their problems and treatments could enhance their awareness of treatment goals, improve their compliance with treatments, increase the effectiveness of intervention,[15] and enhance their self-management and QOL.[16]

Given the complexities of the prevention and treatment of Beta-thalassemia, and due to the increased longevity of these patients we should try to offer some effective ways to improve the quality of life of these patients.

Due to the major developments in science and technology and the development of nursing science as well, the need for extensive research to improve the quality of nursing care.

Nurses compared with other medical professionals have more time for becoming familiar with patient and his problems in term of problems that affects the quality of life of patients with thalassemia. The aim of this study was to examine the effects of a nurse-implemented orientation program on QOL among patients with thalassemia.

Materials and methods

This quasi-experimental study was conducted in 2013–2014. The study population comprised all patients with thalassemia major who referred to Hajar Hospital, Shahrekord, Iran, for receiving blood transfusion. The sample size was calculated by using the findings of the past study conducted by Alijany-Renany.[17]

Subsequently, with a confidence interval of 95% and a power of 0.80, the results of the sample size calculation formula showed that eighteen patients were needed for each study group. However, for having sound statistical analyses and considering the attrition rate, we recruited 30 patients for each group. The study sample was drawn by using the convenience sampling method. Patients were included if they were desired for participation in the study, had an age of sixteen years or older, had no healthcare professional among their family members, were able to read and write Persian, and had no severe hearing or visual problems affecting their orientation to place, time, and person. The exclusion criteria were developing infectious diseases or severe physical complications. Patients were randomly allocated to either the intervention or the control groups by using a table of random numbers. Three patients from the intervention group voluntarily withdrew from the study and two patients from the same group left the study due to changing their residence.

We collected data by using three questionnaires including: a) demographic questionnaire, b) Thalassemia Quality of Life Questionnaire (TQOLQ), and c) the 36-item Short Form Health Survey (SF-36). The demographic questionnaire consisted of patients' personal characteristics and clinical data. The TQOLQ was developed by Allahyari et al., based on the Idiopathic Thrombocytopenic Purpura Quality of Life Questionnaire. It contains eight items for investigating QOL among patients with thalassemia and had 0–6 Likert-type responses for scoring each items of the TQOLQ. Lower scores reflect higher QOL. The validity of the TQOLQ has been confirmed by assessing its content validity; Cronbach's alpha of the questionnaire was 0.84 based on a previous study.[18] We also used the SF-36 for evaluating patients' general QOL. This questionnaire is used for assessing health-related QOL and it consists of 36 items in eight domains of physical functioning, social role functioning, physical role functioning, emotional role functioning, mental health, vitality, bodily pain, and general health perceptions. These 36 items are scored on 0–100 scale—the higher the score, the better the QOL.[19] Previous studies have reported that the Persian SF-36 is a

reliable instrument for assessing QOL. Montazeri et al., translated the SF-36 into Persian and reported Cronbach's alpha values of 0.65–0.90 for it.[20]

Primarily, we invited the study samples to complete the demographic questionnaire, the TQOLQ, and the SF-36. Patients in the intervention group attended an orientation program which included the three steps of inauguration, implementation, and closure. In order to enhance the effectiveness of the orientation program, we divided patients in the intervention group into three sub-groups and oriented each group independently.

During the inauguration step, participants and researchers got familiar with each other and the goals of nurse-patient relationship (i.e. fulfilling patients' needs, improving their health, enhancing their personal autonomy, and minimizing complications) were explained to the samples. Moreover, patients' potential and actual problems in areas such as health behaviors, dietary and treatment regimens, and mental health were identified through performing an assessment of patients and taking their medical history. A checklist was used for assessments and recording the medical history. Two weeks after the inauguration step, we took the implementation step. In this step, patients received educations in three sessions with 60–90-minute. The contents of these three sessions were respectively as follows,

1. Explanation of the thalassemia disease and its new treatments;
2. Explanation of concepts such as hemosiderosis and splenectomy as well as strategies for preventing of infection and activity-related fatigue;
3. Explanation of dietary and treatment regimens as well as strategies for coping with psychological problems.

All educations were provided by using the lecture and the question-and-answer methods. At the beginning of the second and the third sessions, we asked questions about the materials presented in the preceding session(s) and reviewed them. Moreover, patients' questions were answered at the end of each session and they were provided with a written pamphlet containing a summary of the presented materials. At the end of the last session, we provided a comprehensive booklet to the patients which contained all contents of our educations. In the final closure step which was taken two weeks after the second step, we overviewed educations, acknowledged patients' participation in the study, and introduced useful educational websites, books, and articles for obtaining complementary information regarding thalassemia. In addition, we re-assessed patients' educational needs by using a self-administered checklist.

Unfulfilled needs were identified and patients with unfulfilled needs were re-educated individually. One month after the closure step, patients were invited to re-complete the questionnaires.

Data were analyzed by performing the Chi-square, and the paired and independent samples t- tests by using the SPSS Ver. 13 software.

This study was approved by ethical committee of Tarbiat Modares University, Tehran, Iran (No: 52.5367). All participants had right to voluntarily participate in the study or withdraw from it. Moreover, they were informed that their information will remain confidential. Written informed consent was obtained from all samples. At the end of the study, patients in the control group were also received all contents of educations .Limitation of this study was the short time intervention. Further studies are suggested to be conducted in this patients of longer time at younger ages.

Results

Demographic data of participants are shown in table 1. The results showed that both groups were comparable in term of demographic characteristics. Since the results of the Kolmogorov-Smirnov test revealed that all study variables had a normal distribution, we used parametric statistical tests for analyzing the data. Accordingly, the independent-samples t-test showed that the study groups did not significantly differ from each other

regarding the aforementioned variables (P>0.05. Moreover, the Chi-square test revealed that there were no significant differences between the two groups in terms of the education and the employment status of the parents of patients (P> 0.05). (The most frequency participants in education level in both groups' diplomas also most frequency of father's jobs was self-employed and mother's job was housekeeping.

TQOLQ and SF-36 scores are shown in tables 2 and 3. The results of the independent-samples t-test showed that neither before nor after the study the control and the intervention groups were significantly different from each other concerning the scores of TQOLQ and SF-36.

Table1. Demographic characteristics of thalassemia patient (n=55)

Characteristic	Mean(SD)[a]		P[b]
	Experimental	Control	
Age (year)	21.23 (5.46)	21.40 (5.04)	0.908
Height (centimeter)	158.10 (11.57)	157.96 (9.50)	0.962
Weight (kilogram)	50.03 (10.07)	47.04 (12.80)	0.336
Age at diagnosis (month)	11.57 (12.71)	9.64 (7.89)	0.405
Blood transfusion interval (day)	24.67 (8.70)	24.0 8 (9.12)	0.809

[a]Standard deviation, [b]Independent t-test

Table 2. The means of TQOLQ scores in both groups before and after the study

TQOL	Control (n=30)	Experimental (n=25)	P
Pretest	1.04 (1.80)	1.81 (1.20)	0.957
Post test	1.25 (0.99)	1.12 (1.65)	0.140
Paired t-test	P=0.056	P=0.537	

Table 3. The means of SF-36 scores in both groups before and after the study

HQOL SF-36 scores	Time	Control (n=30) Mean (SD)	Paired t-test	Time	Experimental (n=25) Mean (SD)	Paired t- test	P[a]
Physical functioning	Pretest	85.16 (13.67)	P=0.173	Pre-test	87.20 (11.82)	P=0.410	0.647
	Post-test	90.33(14.79)		Post-test	88.60(12.70)		
Role limitations due to physical health	Pretest	65.55(41.50)	P=0.463	Pre-test	64.00(39.58)	P=0.341	0.983
	Post-test	72.22 (37.22)		Post-test	72.00 (39.22)		
Role limitations due to emotional problems	Pretest	73.33 (29.31)	P=0.739	Pre-test	78.00 (20.81)	P=0.588	0.917
	Post-test	75.83 (32.48)		Post-test	75.00 (25.00)		
Energy/ fatigue	Pretest	66.83 (22.57)	P=0.459	Pre-test	68.20 (19.67)	P=0.464	0.106
	Post-test	70.33 (13.95)		Post-test	63.20 (18.19)		
Emotional well being	Pretest	68.66 (20.18)	P=0.188	Pre-test	69.32 (16.27)	P=0.513	0.114
	Post-test	74.70 (18.20)		Post-test	66.56 (19.28)		
Social functioning	Pretest	82.50 (20.39)	P=0.133	Pre-test	80.00 (20.41)	P=0.913	0.052
	Post-test	89.16 (16.65)		Post-test	79.50 (19.32)		
Pain	Pretest	80.66 (20.54)	P=0.358	Pre-test	79.00 (18.28)	P=0.294	0.089
	Post-test	84.08 (21.42)		Post-test	73.00 (23.80)		
General health	Pretest	66.33 (23.85)	P=0.393	Pre-test	68.60 (19.60)	P=0.140	0.111
	Post-test	70.83 (20.76)		Post-test	61.60 (21.34)		
Total	Pretest	73.63 (17.18)	P=0.180	Pre-test	74.29 (13.93)	P=0.566	0.152
	Post-test	78.42 (15.53)		Post-test	72.48 (14.81)		

[a]Independent t-test

Discussion

The findings revealed that the mean scores of all domains of SF-36 of participnts were less than 85. Zarea et al., reported the similar finding.[21] QOL in patients with thalassemia is negatively affected by many factors such physical, socioeconomic, and

psychological states of patients and their families.[22] Hadi et al.,[11] Clarke et al.,[23] and Torcharus and Pankaew[24] also reported the significant negative effects of thalassemia on different aspects of patients' QOL.

We also found that in both the control and the intervention groups, the highest score of QOL was related to the physical functioning domain. Gollo et al., also reported a score of 86.1 for the physical functioning domain which was higher than the scores of other domains of SF-36.[10] On the other hand, the lowest score was related to the emotional role functioning domain. Hadi et al., also reported that among the domains of the SF-36, thalassemia patients' emotional role functioning score (67.86) was the lowest one.[11] These findings can be attributed to the fact that thalassemia care in Iran mainly focuses on managing patients' physical problems rather than other aspects such as psychological problems. Consequently, patients usually feel higher QOL in the physical functioning domain. However, despite considerable negative effects of thalassemia on patients and their families' emotional and psychological health, they are usually neither assessed nor cared for their emotional or psychological problems. These findings highlighted the necessity for providing consultation and psychological care services to these patients.

Study findings also revealed that the intervention had no significant effect on patients' QOL. The mean age of patients was greater than 20 years. Most of the complications of thalassemia start to develop at the earlier ages of life, as early as the age of six months; hence, at older ages, patients with thalassemia are usually suffering from severe effects of both thalassemia and its associated complications. This could be the reason behind the ineffectiveness of our short-term intervention in improving patients' QOL.

Moreover, chronic conditions, such as thalassemia, and their complications and problems negatively affect different aspects of patients' lives. For instance, the chronic condition of thalassemia damages patients' body image and requires them to change their lifestyles.[25] Naderi et al., found that 50.8% of 15–24 years-old patients participating in their study suffered from psychological problems such as depression, anxiety, and social role dysfunction and hence, were greatly at risk for developing mental disorders.[26] Tabarsi et al., also reported that patients with thalassemia have different psychosocial and economic problems which impair their QOL.

Accordingly, these problems include fatigue, despair, low self-confidence, public's negative reactions to thalassemia, limited access to physicians of different specialties, lack of knowledge related to thalassemia, scarcity of required medications and equipments, low-quality financial and family supports, and families' inability to provide the required services.[27]

All these factors might also have contributed to the ineffectiveness of our intervention. Accordingly, more long-term strategies which are implemented from the early ages of patients' lives are needed for generating significant results.

Conclusion

Thalassemia negatively affects all aspects of patients' QOL and faces them with different physical and psychosocial problems. Patients with thalassemia need different types of physical and particularly psychological and emotional care. Given the chronic nature of the disease and the severity of associated complications, a short-term orientation program, like our intervention, would be insufficient for improving patients' QOL. Accordingly, thalassemia care services should be provided over a long period of time for achieving significant outcomes. It seems that the results of this research will help to engage patients in the care and treatment effectiveness.

Acknowledgments

We would like to express our deep gratitude to the staffs of the Thalassemia Care Unit of Hajar Hospital, Shahrekord, Iran, as well as the patients with thalassemia who participated in the study. This paper was extracted from a Master's thesis approved and funded by Tarbiat Modares University, Tehran, Iran. We would like to thank this authorities of this university for their financial support.

Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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