



## Original Article

# Effect of a Mobile-Phone Mediated Based Education on Self-Care Behaviors of Patients with Thalassemia Major

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## ABSTRACT

**Introduction:** One way to improve the quality of life of the patients with thalassemia major is to enable them through education. The present research aimed to explore the effects of an educational intervention through mobile phones on self-care behaviors of the patients with thalassemia major

**Methods:** In this quasi experimental study, which was done from May to January in 2017, 91 patients were enrolled who were suffering from thalassemia major. The census sampling method was performed with random allocation of interventional and control groups. Educational intervention was only applied to the intervention group. The study instrument was a questionnaire which was filled out by the patients before and two months after the educational intervention. For data analysis, statistical tests including independent samples t-test, paired-samples t-test, Mann-Whitney test and Wilcoxon test, were used through SPSS ver.13 software.

**Results:** Prior to the intervention, the mean scores of knowledge, attitude and self-care behaviors were not significantly different between the intervention and control groups. After the intervention, however, there was a statistically significant increase in the aforementioned scores in the intervention group, but there was no statistically significant increase in scores of the control group.

**Conclusion:** The present findings showed the positive effect of the mobile-phone mediated education on knowledge, attitude and self-care behaviors of the patients with thalassemia major. Therefore, the use of mobile phone is recommended as an effective way of transferring instructional material as related to self-care to patients with thalassemia major particularly when access to them is limited.

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## Introduction

Thalassemia is considered a widely prevalent congenital hemoglobin disorder worldwide.<sup>1</sup> Beta thalassemia is viewed a health problem in the Mediterranean area, middle east, India and south-east Asia.<sup>2</sup> 20 thousand patients and about 2-3 million others (4% of population) in Iran have been reported suffer from this disease. About 10% of the residents of Hormozgan province carry the gene.<sup>3</sup>

To prevent chronic anemia and bone modifications, these patients need to constantly receive blood. Within the past 2-3 decades, blood reception has significantly lengthened the length of life and life expectancy of the patients with thalassemia major. However, the increasing use of this therapy has had such side effects as iron overload, iron accumulation in the body, endocrine defect, heart disease, liver fibrosis and the risk of viral infections.<sup>4</sup> To prevent the above-mentioned damages as a result of iron sedimentation, chelation drugs are normally used. It has been indicated in a body of research that the side effects of thalassemia major can vary in developing countries due to an unprincipled application of chelation therapy.<sup>5</sup> Unfortunately, besides the side

effects of chelation drugs, there are other factors that prevent patients from undergoing the complete therapeutic process.<sup>6</sup> There is a high load of mental pressure imposed on many aspects of these patients' life, including education, leisure and physical activities often due to anxiety, isolation and depression.<sup>7</sup> The side effects of this disease are further intensified with aging and patients get more and more frustrated.<sup>8</sup> There is a reciprocal relationship between the disease and quality of life, especially among patients with chronic diseases. The primary goal of treating these patients is to enhance their quality of life through reducing the effects of this disease.<sup>9</sup> Specialists in such fields as medical sciences and psychology have investigated the effect of different medical and psychological interventions on the quality of life of patients with chronic diseases. In recent years, the primary goal has essentially been to improve self-care through an educational intervention. However, what has dominated the recent years have been self-care-based interventions the primary goal of which has been to promote the quality of self-care. These interventions require a precise recognition of care needs, evaluation of patients' potentials of self-care and educating proper self-care skills in a desired communicative context.<sup>10</sup>

Education is a special part of a self-care program which can actively involve patients in taking a good care of themselves and resist against their current state.<sup>11</sup> There has been a variety of methods used to educate patients including oral, written materials, images, videos, telephone calls, the internet system and so on.<sup>10,11</sup>

People with chronic diseases require constant care which is often complained about by healthcare providers and the patients, in turn, complain about lack of time to receive such care. The patients are often unable to attend educational programs. Mobile communications have provided a chance of externalizing healthcare services from hospitals and clinics to where patients live.<sup>12</sup> An ever increasing use of mobile phones has made them a new means of tele-self-care and a link between patients and healthcare providers.<sup>13</sup> Using the phone to provide healthcare services not only cuts down on costs and facilitates access to care services, but also improves patient and care provider relationship. It also eliminates the time and place limitations. Some researchers pointed out communication over phone as a method for education and follow-up of chronic diseases. However, there is still a pressing need for further research into the area.<sup>12</sup> In this study, the intervention group experienced a new type of education and their knowledge improved without getting into the classroom and getting their time and evaluate their performance in self-care and receive feedback. Also, educational content was presented based on their individual needs and the level of literacy and understanding. Therefore, the present research aimed to explore the effects of mobile phone mediated education on the self-care behaviors of patients with thalassemia major.

## Materials and methods

As an quasi-experimental study which was done in 2017 from May to January, the present research targeted patients suffering from major thalassemia who visited Hazrat Abolfazl hospital in Minab - Hormozgan province, southern Iran. Due to the limited sample size, a census was followed and all patients who met the inclusion criteria and consented to participate entered the study. The other inclusion criteria were willingness to take up phone-mediated education, having an active medical file in the thalassemia ward of the hospital and regular visits to the hospital to receive the required services, being 13+ years of age, having a mobile phone either of one's own or their family, having no mental or behavioral disorder, nor a hearing or speech problem.

The exclusion criteria were reluctance to take part in the research, attendance of fewer than 3 sessions in the educational program, a history of participating in a similar educational programs. According to the existing medical files in the thalassemia ward, 102 patients met the inclusion criteria. The patients' names were classified randomly to urban and rural groups, based on the place of residence. Then, each group was further divided into a control and an intervention group. From among them, 6 subjects were excluded from the control group (1 due to

hospitalization and 5 due to an unwillingness to take part in the research). 5 patients were excluded from the intervention group (3 due to their unwillingness to participate and 2 for hearing or depression problems). As a result, the control group ended up with 45 and the intervention group with 46 participants eventually.

The data collection instrument was a questionnaire developed by the researcher which comprised four sections. The first section contained the respondents' demographic information and background information in 11 questions about sex, age, education, place of residence, marital status, type of Chelation drugs taken, frequency of taking Chelation drugs on a weekly basis, frequency of injections on a monthly basis, splenectomy and other family members with thalassemia.

The second section consisted of items concerning the patients' knowledge. 20 items were included which enquired about patients' awareness of the disease and its side effects, self-care behaviors, chelation therapy, blood injection, consequences of the disease and therapeutic recommendations. The respondents were supposed to choose true, false or don't know in response. Every true would be scored as 1 while every false/don't know would receive 0. The maximum score would be 20. The third section involved attitude questions. A total number of 20 items were included which enquired about the patients' attitude towards their present and future status, the effect of therapeutic programs and self-care behaviors. The responses were supposed to be made in a 5-level Likert scale (totally agree, agree, neutral, disagree, totally disagree). 'Totally agree' would receive 5; 'agree' would be rated as 4; 'neutral' would receive 3; 'disagree' would get 2 and finally 'totally disagree' would be rated as 1. The minimum attitude score was 20 and the maximum score was 100. The fourth section of the questionnaire dealt with showing self-care behaviors in the form of 44 items. Those exploring the respondents' nutritional status were 23 in number. 2 items looked into physical activities. 4 other items dealt with the use of chelator. The extent to which injections were used was explored through 3 items. 10 items enquired regular visits to a doctor and finally 2 items asked about smoking (cigarettes or hookah). The options were always, often, occasionally and never which were respectively rated as 3, 2, 1 and 0. The performance score was once estimated and reported as a whole and once again separately for each section.

The questionnaires were provided to a 5-member team of health education experts, nutritionists and doctors familiar with thalassemia healthcare. Content validation was done to ensure the validity of the questionnaire. To establish the reliability of the questionnaire, the test-retest method was followed. Then, Spearman's test of internal consistency was run which turned out to be 0.85 for each knowledge item and 0.71 for the performance items, to estimate the reliability of the attitude, Cronbach's alpha was estimated (0.71).

The informed consent was received from all participants. Participants were reassured their information would remain confidential. The questionnaires were filled out

twice, once before the intervention in a face to face interaction and once gain 2 months after the mobile phone mediated intervention. To facilitate responding to the attitude test, an instrument was designed to guide the patients to fully understand the 'agree', 'totally agree', 'disagree' and 'totally disagree' options. The instrument includes a strip of paper with two whole red and blue for opposition to an agreement.

The phone-mediated educational intervention occurred through six 15-18 min calls within a month. The calls were made at the patients' convenience from 8 a.m. to 8 p.m. The topic of the first call was familiarity with the disease. The topic of the second call was significance of taking chelation drugs. The third phone call was about the side effects of thalassemia while the fourth call addressed nutrition and thalassemia. The fifth phone call dealt with physical activity and the disease while the sixth call was concerned with smoking. The content of each call after greeting was an examination of the patient's knowledge of the topic and the source of information. Then the educational content was posed in a question and answer format. As an instance, the subject was asked: "Name a few iron-loaded food materials". Then guided by the patient's answer, corrective or complementing information was provided. Moreover, in each call, the patient was asked about the extent to which she/he followed the diet, physical exercises, drugs and therapy recommendations. In the event of non-adherence, the reason was looked for and a solution was suggested with the help of the patients themselves. So as to answer patients' probable questions, telephone researcher was given to them. In each call the questions asked were recorded and after consultation with the doctor, the questions were answered

The educational content of each call was derived from the Published books of Thalassemia International Federation as well as the comprehensive service package specific to thalassemia patients published by the ministry of health press.<sup>14</sup> After the initial 6 calls, 6 educational pamphlets fitted to the content of each of the six phone calls were availed to the patients in the intervention group. Meanwhile all participants, both in the control and intervention groups had access to all routine care services provided in the hospital. In order to review the educational content and remind the performance of self-care behaviors within two months of waiting, the participants were contacted monthly. Data were analyzed through SPSS version 13 (IBM, Armonk, NY, USA).

To describe the data, descriptive statistics such as frequency, mean and standard deviation were used. To check the normality of the distribution and homogeneity of variances, Kolmogorov-Smirnov test were used. As for inferential statistics, in order to compare the mean scores of the control and intervention groups before and after the intervention, independent and paired t-tests were used. Or, the non-parametric counterparts were used such as Mann-Whitney U-test and Wilcoxon's test as well as chi-squared and Fisher's test.

## Results

The mean age of the participants in the intervention and control groups were respectively 20.11 (SD= 4.8) and 20.56 (SD= 5.8). No statistically significant difference was observed between the two groups. Similarly, no statistically significant difference was observed between the groups in terms of sex, marital status, places of residence and education level (Table 1).

**Table 1.** Demographic characteristics of the study sample

	Intervention N (%)	Control N (%)
Sex		
Female	23 (50)	25 (55.6)
Male	23 (50)	20 (44.4)
Chi-square	P=0.59	
Marital status		
Married	0 (0)	1 (2.2)
Single	46 (100)	44 (97.8)
Fisher Exam	P=0.49	
Educational status		
Illiterate	8 (17.4)	4 (8.9)
Primary	9 (19.6)	10 (22.2)
Secondary1	15 (32.6)	15 (33.3)
Secondary2	10 (21.7)	10 (22.2)
Pre-university	2 (4.3)	4 (8.9)
Collegiate	2 (4.3)	2 (4.4)
Mann-Whitney	P=0.38	
Residence		
City	15 (32.6)	18 (40)
Village	31 (67.4)	27 (60)
Chi-square	P=0.46	

Table 2 represents the distribution of the subjects in terms of the disease characteristics in both the intervention and control groups. Except for the drug used, no statistically significant difference was observed between the two groups.

**Table 2.** Frequency distribution according to the characteristics of disease in the intervention and control groups

	Intervention N (%)	Control N (%)
Chelation drug		
Subcutaneous	34 (73.9)	32 (71.1)
Oral	10 (21.7)	4 (8.9)
Both of them	2 (4.3)	9 (20)
Chi-square	P=0.02	
Frequency of blood transfusion a month		
Once	7 (15.2)	8 (17.8)
Twice	39 (84.8)	37 (82.2)
Mann-Whitney	P=0.74	
Splenectomy		
Yes	8 (17.4)	15 (33.3)
No	38 (82.6)	30 (66.7)
Chi-square	P=0.08	
History of the Thalassemia In the family		
Yes	19 (41.3)	23 (51.1)
No	27 (58.7)	22 (48.9)
Chi-square	P=0.34	

To check the normality of the data and homogeneity of variances Shapiro test was used. As for the knowledge of thalassemia, there was no statistically significant difference between the two research groups prior to the intervention. However, the two groups revealed significant differences after the intervention. The results indicated a statistically significant increase in the patients' knowledge in the intervention group ( $P<.001$ ) (Table 3).

**Table 3.** Average score of knowledge, attitude and self-care behaviors in the intervention and control groups

	Intervention Mean(SD)	Control Mean(SD)	P-Value
<b>Knowledge</b>			
Before	10.6 (3.55)	1.4 (4.33)	$P=0.58^*$
After	13.34 (3.3)	1.24 (3.87)	$P=0.001^*$
Wilcoxon	$P=0.001$	$P=0.434$	
<b>Attitude</b>			
Before	67.63 (7.58)	6.11 (9.7)	$P=0.40^{**}$
After	69.63 (7.44)	6.73 (7.77)	$P=0.001^{**}$
Paired t-test	$P=0.743$	$P=0.618$	
<b>Nutritional behaviors</b>			
Before	34.3 (6.2)	3.71 (5.76)	$P=0.2^{**}$
After	37.65 (7.71)	3.77 (5.77)	$P=0.001^{**}$
Paired t-test	$P=0.001$	$P=0.323$	
<b>The use of chelation therapy</b>			
Before	8 (2.36)	7.37 (2.32)	$P=0.26^*$
After	9.15 (2.52)	7.28 (2.22)	$P=0.001^*$
Wilcoxon	$P=0.001$	$P=0.317$	
<b>Blood injection</b>			
Before	5.41 (1.98)	5.35 (1.93)	$P=0.86^*$
After	6.43 (1.92)	5.37 (1.94)	$P=0.01^*$
Wilcoxon	$P=0.001$	$P=0.37$	
<b>Referred to specialists</b>			
Before	2.47 (1.91)	2.11 (1.9)	$P=0.32^*$
After	3.41 (1.91)	2/11 (1.86)	$P=0.002^*$
Wilcoxon	$P=0.001$	$P=1$	
<b>Physical activity</b>			
Before	1.3 (1.64)	1.4 (1.54)	$P=0.57^*$
After	1.73 (1.71)	1.42 (1.52)	$P=0.40^*$
Wilcoxon	$P=0.001$	$P=0.317$	
<b>Smoking</b>			
Before	5.84 (0.46)	5.73 (0.83)	$P=0.89^*$
After	5.89 (0.37)	5.73 (0.83)	$P=0.62^*$
Wilcoxon	$P=0.175$	$P=0.1$	
<b>Performance</b>			
Before	57.36 (8.54)	5.68 (8.23)	$P=0.13^{**}$
After	64.28 (11.11)	5.71 (8.22)	$P=0.001^{**}$
Paired t-test	$P=0.001$	$P=0.66$	

\*Mann-Whitney, \*\*T-test

No statistically significant difference was estimated between the control and intervention groups prior to the intervention. There was a significant differences in term of attitude towards the disease, nutritional behavior and the use of chelation drugs in the intervention group After after application of intervention. ( $P<.001$ ) (Table 3). In terms of visits for blood injection, the two research groups did not diverge significantly prior to the intervention, either. Later on, however, they were found to diverge as the intervention group showed a significantly higher rate of visits paid for injection than the control group ( $P<.001$ ) (Table 3). Also the result showed that the number of patients who referred to specialist physician increased significantly in

intervention group after the educational program ( $P<.001$ ), but no statistical changes were observed in control group in this regard (Table 3). As for pre-intervention physical activities, no statistically significant difference was observed between the two research groups. After the phone-mediated intervention still no difference was observed. Therefore, the phone-mediated intervention was found to have no effect on increasing physical activities (Table 3). As concerns smoking (cigarettes or hookah), the two groups showed no statistically significant difference in advance of the intervention. Still, no difference was observed between the same groups after the intervention. It appeared that the phone-mediated intervention had no effect on lowering smoking in patients with thalassemia major (Table 3).

As for the overall self-care behaviors score, the two research groups did not diverge significantly prior to the intervention. Nevertheless, the same groups diverged significantly after the intervention which indicates that the phone-mediated intervention significantly affected the self-care behaviors of the patients with thalassemia major ( $P<.001$ ).

## Discussion

The present research aimed to explore the effects of a phone mediated educational intervention on the self-care behaviors of patients with major thalassemia. The results indicated the positive effect of such an intervention on the participants' knowledge, attitude and self-care behaviors (except for physical activity and smoking). In their research, Lee et al. obtained a significant positive correlation between the knowledge of patients with thalassemia and their adherence to the therapy.<sup>15</sup> The present findings indicated a significant increase in the patients' knowledge score in the intervention group after the phone-mediated intervention. Other investigations by Goodarzi revealed that a texting-mediated and mobile phone-mediated education managed to significantly raise the knowledge of patients with type 2 diabetes.<sup>16</sup> In their study, Baker et al., observed a similar rate of increased self-awareness among all age groups of the sample after a phone-call mediated intervention.<sup>17</sup> In the present research, both control and intervention groups had access to all routine care and instructions available at hospitals. The fact that no significant increase was found in the participants' knowledge in the control group shows that routine instructions in the hospital may not be effective on their own. Moreover, the educational content, written and orally-communicated instructions may contain unfamiliar phrases and concepts that could fail the readers.

What really matters in fighting against any health-related problem is people's attitude towards that problem is. If people believe they are exposed to a disease or its side effects, they can naturally stand against it more easily.<sup>18</sup> The present findings revealed that mobile-phone mediated education has managed to positively affect the subjects' attitude in the intervention group. It seems that people's perception of the severity of

the disease and its side effects and the benefits of self-care behaviors managed to improve the subjects' attitude in the intervention group. The present result of the effectiveness of mobile-phone mediated education in improving subjects' attitude is consistent with the study of Person et al. In their study, most participants had a positive attitude toward SMS to acceptance of tuberculosis test and treatment. They believed that SMS was effective in reminding the patients of their appointments with a doctor and taking medication.<sup>19</sup> Moreover, the present findings indicated that mobile phone mediated education can lead to a significant increase in the patients' nutritional behavior. Blood injection in patients with thalassemia major causes iron accumulation and severe damages to internal limbs.

Many foods such as those containing calcium, those with much fiber due to their phytate content or tea and coffee that contain polyphenolic compounds can play a key role in reducing iron absorption through bowels.<sup>20</sup> Similarly, Atienza et al. indicated that using portable devices such as tablets or smart phones can contribute to one's diet and fill it with more vegetables and grains.<sup>21</sup> Beasley et al., indicated that using dietary data recording and monitoring software as compared to daily notes did not manage to make subjects follow their diet more effectively. The reason could be the time-consuming act of recording the information in software as compared to the simple manual note taking.<sup>22</sup> The present research not only provided the educational content through phone calls but also evaluated the extent to which the patients followed the self-care behaviors especially their nutritional behaviors. If a participant was found not to have followed the self-care activities, the underlying reason was investigated and a solution was thought of with the help of the participant themselves.

The present findings revealed that the phone-mediated education managed to improve the use of chelation drugs in the intervention group and regulate patients' visits to hospital for blood injection.<sup>23</sup> It was shown in Lee et al.'s investigation that only 43% of the patients were aware of the importance of regular blood injection. It was concluded that these patients' low awareness was a key reason why they rarely followed a regular and orderly process of blood injection. Leonard et al. and Creary et al., indicated that using computer-based software helped to improve adherence to chelation drugs in the patients suffering from major thalassemia and Sickle cell disease.<sup>24,25</sup> Similarly, Person observed that short message services through mobile contributed to the patients' adherence to tuberculosis therapy.<sup>19</sup> The present results revealed that mobile phone mediated education helped to improve the state of thalassemia patients referring to specialists in the intervention group. The findings reported by Chen et al., indicated that using text messaging and reminders through mobile phones contributes to subjects' attending the healthcare centers.<sup>26</sup>

In their research, Cho et al., observed that short message services led to a significant increase in the presence rate of patients using blood fat reductive therapies in healthcare centers.<sup>27</sup> Among the most

prevalent reasons why patients did not attend healthcare centers were occupational or familial commitments, undesired patient and care providers relationship and undesirable clinical experiences.<sup>28</sup> In the present research, participants in the intervention group were provided with the researcher's contact information. In each call, their questions and problems were answered after visiting the thalassemia ward doctor. The questions asked were mostly about the side effects and they were asked to refer to their specialist so as to solve their problem. Regular physical activity has inevitable health-related and economic benefits and can reduce preterm mortality rate and the side effects of chronic diseases. It can also improve mental health and increase the capacity of production.<sup>29</sup> The present findings revealed that mobile phone mediated education had no significant effect on increasing the physical activity of the patients with thalassemia major. In the present study, the researchers emphasized on the benefits of physical activity and its effect on the functioning of body organs and improving the patients' mood. At the closure of the intervention, the participants were provided with a pamphlet on the benefits of physical activity. Lee et al., observed that the patients with thalassemia major had concerns about performing physical activity. They also believed that daily routines should be limited and even in some cases patients were forbidden by their family to do physical activity.<sup>15</sup> In their study, Paul et al., indicated that mobile phone applications added to daily walks among patients who had a brain stroke.<sup>30</sup> Similarly, Gillian. Indicated that modern technology mediated interventions help to improve physical activity.<sup>31</sup> One reason why the mobile phone mediated intervention was ineffective in promoting physical activity could be the limited facilities and hot weather of summer in the setting of this research.

Therapeutic instructions to patients with thalassemia for preventing osteoporosis emphasize on refraining from smoking.<sup>23</sup> No significant change was observed in the present research in the participants smoking behavior after the intervention. In their research on patients visiting the emergency ward, Fingrut et al., observed that 44% of the participants were willing to receive mobile phone mediated services to quit smoking. The same rate was reported to be 17% for the short message services and 40% for email correspondence.<sup>32</sup> In some other research, Lawrence et al. observed that a 2-month mobile-phone mediated consultation and follow-up led to an increased rate of quitting smoking.<sup>33</sup> It is mentioned that in Lawrence et al. study research the participants were selected from among those willing to quit smoking. There might be a need for more extensive interventions or more education on the side effects of smoking, as well as instructions on applying theory-based education through the medium of mobile phones. The overall findings of the present study attested to the effectiveness of education through the medium of mobile phones in promoting self-care behaviors among patients with thalassemia major.

Using a mobile phone can be a simple and cost-effective way to help people to achieve health-related

goals. It is manifested through enabling people to take up an active role in managing their own health. Those with chronic diseases require long-term care provision and often have limited access to healthcare services due to the distance problem. Through mobile phones, however, therapeutic programs and follow-ups can be easily done. Among the limitations of this research was occasional disruption in mobile phone communication services. The short duration of the intervention and uncontrolled blood indices such as patients' ferritin level were some other limitations which need to be compensated for in future body of research.

## Conclusion

The present findings represent the positive effects of mobile phone mediated educational intervention on the knowledge, attitude, and self-care behaviors of patients with thalassemia major. Therefore, using mobile phone technology as a way of transferring educational content on self-care to these patients especially when they are not easily accessible is recommended.

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## Ethical issues

None to be declared.

## Conflict of interest

The authors declare no conflict of interest in this study.

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