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Study of the impact of religious care education on the life expectancy and spiritual health of adolescents suffering from thalassemia major

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Abstract

Given that adolescents with thalassemia major have low life expectancy and spiritual health due to disease, treatment and complications, and given that religious care is an easy, uncomplicated and inexpensive method, this study was conducted with the aim of determining the effect of religious care education.The present quasi-experimental study was performed on34 teenagers referring to Ali Asghar Hospital. Research tools included questionnaires:demographic characteristics, Schneider's life expectancy, and Paloutzian and Ellison's spiritual health scale.the intervention group took part in six educational sessions of 40-60-minute, religious care. The results showed that the two groups had no statistical difference in terms of the total score of life expectancy and the average score of spiritual health before the intervention, but the comparison of the average score of life expectancy and the average score of spiritual health after the intervention showed a statistically significant difference between these two groups.Considering the importance of life expectancy and spiritual health in the recovery and follow-up of patients from the treatment regimen and treatment follow-up, spiritual and religious care education, which is followed by the improvement of spiritual health and life expectancy, can be very beneficial for adolescents with thalassemia major.

Keywords:religious care, life expectancy, spiritual health, Thalassemia

Introduction

Thalassemia includes a group of autosomal recessive diseases with diverse phenotypes resulting in globin synthesize impairments (1).

Beta thalassemia is among the most prevalent kinds of thalassemia which results in impairments in beta hemoglobin synthesis. Around 240 million people carry this gene across the world and 200,000 infants are annually born with thalassemia. Around 20,000 patients and 2-3 million people carrying this gene (4% of the population) live in Iran. The mean prevalence of thalassemia is higher in Iran compared to the global average since Iran is located in the thalassemia belt. Studies have revealed that 10% of the people living in Bushehr, Khuzestan, Hormozgan, Kerman, Sistan-va-Baluchistan, Gilan, Isfahan, Mazandaran, and Fars carry the genes for this diseases. Beta thalassemia is classified into three categories of mild, moderate, and severe based on the intensity of anemia it results in (2, 3).

Thalassemia major is the most severe form of thalassemia resulting in life-threatening anemia. Patients suffering from this form of thalassemia need a regular blood transfusion to survive (4).

Thalassemia patients are mainly from the young population and at the ages of childhood and adolescence. The complications brought about by thalassemia for adolescents make them experience life with constant anguish and fatigue during their childhood and adolescence and be unable to experience their environment as healthy people (5). Adolescents suffering from thalassemia major have to go through major cognitive, mental, physical, and social changes such as self-image disorders, sexual disorders, social interaction and communication disorders –especially with peers-, bone deformation, feeling of helplessness due to their dependency on others to receive care, concerns of premature death, isolation, depression, anxiety, economic disorders, regular blood transfusion, and the use of iron-depleting agents to reduce iron loading (6, 7) all of which result in desperation and lower life expectancy in thalassemia major patients (8). According to Benzene and Berg, being hopeful helps patients control the crisis resulting from the disease in psychological and emotional ways. Other references have also suggested that having hope in life predicts the process of chronic diseases. Life expectancy is lower in thalassemia major patients compared to others. Various studies indicate that thalassemia major patients' life expectancy is significantly different from the life expectancy of those not suffering from thalassemia major (9, 10). Besides, studies suggest that thalassemia patients have a low life expectancy due to fear of premature death following the severe complication resulting from the disease and regular blood transfusion (11). Thus, attempts to increase these patients' life expectancy appear to be of utmost importance.

Spiritual health is among the essential aspects of human health whose consolidation could result in increased life expectancy, better compatibility, attenuated disease process, and general improvements in patients' quality of life and psycho-social status (7). Results of some studies suggest that spiritual health and hope are significant factors in life that help

individuals adjust to the disease, reduce their emotional stress, and improve their psycho-social health (12). Disorders in spiritual health could lead to increased confusion, psychological disorders, depression, feeling of loneliness, and losing meaning in life as well as reducing the body's internal harmony and ability to cope with problems (13). Spiritual health is of utmost significance in thalassemia patients and could influence life expectancy, disease process, and patients' psycho-social health (14). Various studies indicate that teenagers suffering from thalassemia major lack high levels of spiritual health (15). Thus, one could conclude from the aforementioned that improved spiritual life which is followed by higher life expectancy could be quite imperative in thalassemia major patients. Religious care is one of the non-pharmaceutical ways that suits this purpose (16).

Spiritual and religious care in caregiving is a unique aspect of care that cannot be replaced by psycho-social care and gives responses to one's fundamental questions concerning anguish, pain, death, and the meaning of life (17). Spiritual care is a kind of care that identifies peoples' needs when encountered with disease, trauma, or worry and responds to them (18). Caregivers have recently discovered that sensitivity to patients' religious aspect is quite imperative if they plan to provide real and complete healthcare (19). Spiritual care has been known as the most helpful factor to reach a balance in maintaining health and fighting against the disease and is associated with emotional, spiritual, and physical health (20). Two studies have confirmed the impact of spiritual care on the improvement of spiritual health in patients undergoing hemodialysis and patients suffering from amphetamine addiction (13, 17). Besides, previous research indicates a significant and positive relationship between life expectancy and spiritual care (21).

Results of Vaezi (2014) indicated that spirituality enabled women suffering from thalassemia to improve their individual, social, and psychological performance (22). Besides, Bernard et a. (2017) concluded in their study that spirituality could reduce mental disorders, increase life expectancy, and generally increase the quality of life in patients suffering from thalassemia major (23).

The present study was conducted in 2020 in Zahedan seeking to determine the impact of spiritual care education on life expectancy and spiritual health in adolescents suffering from thalassemia major given the importance of life expectancy and spiritual health in the lives of adolescents suffering from thalassemia major, the positive impacts of religious care on various health aspects particularly psycho-social health, the limitations of previous research conducted on spiritual care in thalassemia patients, and the fact that spiritual health is a non-pharmaceutical and harmless method (16).

Method

The present quasi-experimental study was performed on 34 teenagers referring to Ali Asghar Hospital's thalassemia ward. The sample size was considered to be 34 patients considering the study of Erie et al. (5), a confidence interval of 95%, and a test power of 80%. Sampling was conducted randomly and based on a lottery, and participants were randomly divided into two groups of intervention and control. Inclusion criteria included

being aged 15-20, being literate enough to read and write, not having transfused flood over the past six months, and having medical records while exclusion criteria were non-consent to participate in the study, suffering from chronic and severe diseases, and over one incidence of absence from religious care training sessions.

Research tools included the questionnaire of demographic characteristics, Schneider's life expectancy questionnaire, and Paloutzian and Ellison's spiritual health scale.

The demographic questionnaire collected data such as gender, age, literacy, and blood transfusion history.

Paloutzian and Ellison's spiritual health scale is a 20-question question out of which 10 questions evaluate religious well-being and the other 10 assess existential health. The spiritual health score is the sum of scores obtained in these two subcategories and ranges between 20 and 120. Questions are scored on a six-point Likert scale ranging from completely agree to completely disagree. Eventually, people's spiritual health is divided into three categories of low (20-40 scores), moderate (41-99 scores), and high (100-120 scores). This questionnaire has been tested and confirmed in terms of reliability and validity by MozhganAbbasi (2005) in Iran through a study on 238 nursing students from Iran, Tehran, and Shahid Beheshti universities (24,25).

Schneider's life expectancy questionnaire was validated by Schneider, Anderson, Harris, and others in 1991. This questionnaire includes 12 items and has been designed for ages 15 and above. Among the item, four of them assess agency thinking, four assess strategic thinking, and four items are deviant. The test is diagnostic and includes 48 aspects of frustration and hope with items selected covert or overt behavioral manifestations in hopeful or hopeless individuals. The questionnaire's validity and reliability have been confirmed by Yektaii in Iran (26). Questions are scored on a five-point Likert scale ranging from extremely agree to extremely disagree. Final scores obtained from Schneider's test range between 12 and 60. Four items in the questionnaire have negative scores and are scored in reverse (items 3, 5, 7, and 11). Scores of 1-12 indicate low life expectancy, scores of 12-36 indicate moderate life expectancy, and scores higher than 36 indicate high life expectancy.

The research was executed after being approved by the ethics committee of the university, meeting the required coordination, and acquiring the required permits. 34 teenagers were selected from the adolescents suffering from thalassemia major who were referred to the thalassemia ward of Ali Asghar Hospital. Informed consent was obtained from the participants and required information was delivered to them regarding the methods of the research, its purpose, its safeness, information confidentiality, and the possibility to withdraw from the study at any point. The demographic characteristics questionnaire, Schneider's life expectancy questionnaire, and Paloutzian and Ellison's spiritual health scale questionnaire were filled by both study groups before intervention. Then, the intervention group took part in six 40-60-minute religious care training sessions as a group during three

weeks and in the mornings. The contents of religious care training included issues such as faith, patience, recourse, prayer, self-discovery, establishing an unwavering connection with God, reconciliation with people, and communication with others. Educational content for each session was prepared in a structured and well-codified manner based on the study of Erie on teenagers with thalassemia (5, 27), Reihani's study on mothers with premature babies (28), and AsadZandi's spiritual care handbook (29). A cleric took part in the sixth session alongside the author to give lectures on the content of the course and answer participants' questions (the following table demonstrates a complete list of content delivered each session).

The table of educational content on spiritual care for adolescents suffering from thalassemia major

Table 1 - Schedule of religious care education sessions

Session	Contents	Duration
1	Greeting, complete information of the process, getting to know the teenagers' understudy, ensuring participants of information confidentiality, gaining trust, and expressing honesty and compassion	45-60 minutes
2	Greeting, careful listening and attention to physical, psychological, and social problems of patients, offering pamphlets on the disease and answering questions, helping teenagers with the meaning behind the disease and divine fate, reinforcing hope and innermost powers	45-60 minutes
3	Greeting, review of the previous sessions, strive to keep a constant connection with the compassionate lord, encouraging teenagers to read holy Quran, pray, and listen to stories from Quran and Imams' lives, reciting Zikrs and prayers, training on the influences and benefits of charity, explaining the necessity of gratefulness for God's blessings and teaching about the effects of deeds and nigh-time prayers, providing these prayers for the patients to recite	45-60 minutes
4	Greetings, review of previous sessions, answering patients' questions, training on the	45-60 minutes

	importance of knowing one's self, expressing the existential value of humans, trying to focus on one's self and emotions and acknowledging them, identification of human defects, reciting various hadiths and stories in this regard, providing the required facilities to perform religious practices	
5	Greeting, review of previous sessions, answering patients' questions, efforts to communicate and reconcile with people, expressing the effects of the aforementioned, reciting hadiths and stories on communication with others, encouragement to use religious and recreational spaces, encouragement to establish friendly connections with others an socializing with them –especially close friends and relatives	45-60 minutes
6	Greetings, review on previous sessions, answering patients' questions, encouragement to connect with nature and doing what has been recommended by Imams such as looking at running water, verdant trees, beautiful flowers, etc., encouragement to participate in spiritual programs, presence of a cleric to talk to patients and answer their questions, providing a summary of the content and farewell	45-60 minutes

No intervention was performed for the control groups. Questionnaires were filled again by both groups after intervention.

After data collection, SPSS v.16 software was used for statistical analysis. Results of the Kolmogorov-Smirnov test indicated that research data were distributed abnormally so non-parametric tests were used for data analysis. Thus, descriptive tests such as frequency, percentage, mean, and standard deviation were used to describe and analyze data, and Wilcoxon and Mann-Whitney statistical tests were performed at significance levels lower than 0.05.

Results

The mean and standard deviation of patients' age was 17.26±1.5 years while the mean and standard deviation of their history of blood transfusion was 11.76±1.35 years.

58.8% of participants (20 people) were male and 41.2% (14 people were female). Table 2 indicates other demographic parameters. No significant difference was observed between the intervention and control groups in any demographic parameters before intervention (P-value>0.05).

Table 2: comparison of the demographic variables frequency in adolescents suffering from thalassemia major in the two groups of intervention and control

Group / variable		Intervention Frequency (%)	Control Frequency (%)	P-VALUE
Gender	Male	10 (58.8)	10 (58.8)	P>0/05
	Female	7 (41.2)	7 (41.2)	
Religion	Shiite	7 (41.2)	5(29.4)	P>0/05
	Sunni	10(58.8)	12(70.6)	
Ethnicity	Sistani	5(29.4)	7(41.2)	P>0/05
	Baluch	11(64.7)	7(41.2)	
	Persian	1(5.9)	3(17.6)	
Group / Variable		Intervention Mean ±standard deviation	Control Mean ±standard deviation	P-VALUE
Age		16.88±1.31	17.65±1.61	P=0/14
Blood transfusion history (years)		11.35±0.86	12.18±1.62	P=0/11

Results of the Mann-Whitney statistical test indicate that the two groups were not statistically different in terms of total life expectancy score before intervention (P=0.09), but the comparison of mean life expectancy score after intervention indicates a statistically significant difference between the two groups (P=0.02). Results of the Wilcoxon test indicated that the intervention group's mean life expectancy changed significantly after intervention (P=0.000) while the control group's mean life expectancy did not change significantly after intervention (P=0.64). The mean total life expectancy score of the control group improved by 9% in the intervention group and declined in the control group.

The mean total life expectancy score of the participants in the control group was 24.76±3.36 before intervention which falls into the moderate category but this score declined by a small amount (28.47±6.09) after intervention (Table 3).

Table 3: Comparison of mean total life expectancy score of adolescents suffering from thalassemia major before and after intervention in both control and intervention groups

Group / Variable		Before intervention Mean ±standard deviation	After Intervention Mean ±standard deviation	P-VALUE
Life expectancy	Intervention	24.76±7.89	45.6±5.59	P=0.000
	Control	28.3±94.36	28.6±47.09	P=0.64
P-VALUE		P=0.09 Z= -4/66	P=0.02 Z= -3/11	

The two groups were not significantly different in terms of the mean total **spiritual health** before intervention (P=0.12), but a significant difference was observed between the two groups after intervention in terms of the mean total **spiritual health** score (P=0.01). the comparison of the two groups' total religious well-being before and after intervention indicated that the control group's scores had not changed significantly after the intervention while the intervention group had significantly changed (P=0.000). The mean total **spiritual health** score increased by 8.5% in the intervention group and declined by 8.25% in the control group after intervention.

Intervention group participants' total **spiritual health** score (60.05±24.33) were categorized into the moderate class and remained in the same category after intervention although having improved (93.16±64.53). The control group's score was categorized as moderate (55.29±8.46) and remained in the same category although having declined during the intervention (53.52±5.79) (Table 3).

Table 4: Comparison of mean total **spiritual health** score of adolescents suffering from thalassemia major before and after intervention in both intervention and control groups

Group / Variable		Before intervention Mean ±standard deviation	After Intervention Mean ±standard deviation	P-VALUE
spiritual health	Intervention	60.05±24.33	93.64±16.53	P=0.000
	Control	55.29±8.46	53.52±5.79	P=0.06
P-VALUE		P=0.12	P=0.01	

Discussion

Results of the present study revealed that mean total life expectancy and **spiritual health** scores were at a moderate level before intervention and increased significantly after teaching religious care to the intervention group. In this section, studies relevant to the present study will be discussed.

In his study, Jamal Abadi (2017) concluded that the life expectancy of thalassemia major patients was significantly different from those not suffering from this disease. Pourmovahhed demonstrated that 17.4% of teenagers suffering from thalassemia major also suffer from hopelessness (9, 10). Besides, studies indicate that thalassemia patients have a low life expectancy due to fear of mortality resulting from the severe complications of the disease and regular blood transfusion (11). In the study of Mohammadi (2010), the mean spiritual health score of teenagers suffering from thalassemia major was 95.2 and over half of the participants had moderate spiritual health (9). Madmali (2018) also concluded out in his study that adolescents suffering from thalassemia major have a moderate level of spiritual health (15). Results of these studies are consistent with the present study and highlight the importance of paying attention to the aspects of spiritual health and life expectancy in adolescents with thalassemia major.

Gholami et al. (2009) confirmed the influence of 10 one-hour meaning-therapy group training sessions on general health and life expectancy of teenagers suffering from thalassemia (30) which is consistent with the present study but is not entirely generalizable since this study only examined girls.

Erie et al. (2018) discovered that teaching spiritual self-care increased the self-care level of adolescents suffering from thalassemia significantly (5) which is also consistent with our study.

Salami et al. (2015) investigated the impact of spiritual self-care in a group on the life expectancy of patients suffering from coronary artery disease and observed that patients' life expectancy score increased significantly after intervention (31) which is also consistent with our results. In 2017, Ravi et al. confirmed the impact of teaching spiritual care on the anxiety of those taking care of Alzheimer's disease at home (32, 33). This study incorporated concepts similar to the present study such as prayer and faith and is similar to the present study in this regard.

Loureiro et al. (2018) conducted a study seeking to determine the impact of spirituality and religiousness on the mental health and suicide risk of patients undergoing hemodialysis. Items such as faith, meaning, and peace were investigated in these patients and results indicated that the meaning sub-scale was associated with lower suicide risk and depression while the sub-scale of peace was associated with lower anxiety and depression (16). The study of Loureiro is similar to the present study to some extent in terms of the type of intervention but differs from the present study given that it has been conducted in Brazil and the definition of spirituality varies across religions and cultures. Besides, the study is different from the present study in terms of methods, care content, studied group, etc.

Limitations

The limitation of this study was the coronavirus outbreak and the necessity of accurate adherence to health protocols.

Conclusion

According to the present study and previous research, life expectancy level and spiritual health are not high in adolescents suffering from thalassemia and most of these patients suffer from low spiritual well-being and hopelessness. Given the importance of these two variables in patients' recovery and their encouragement to follow the therapeutic regimen and follow up on their treatment, teaching spiritual and religious care which is followed by improved spiritual well-being and life expectancy could be quite useful for adolescents suffering from thalassemia major.

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Conflict of interests

None declared.

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