

The Effectiveness of Self-Management Programs on Self-Efficacy in Patients With Sickle Cell Disease

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Background: Patients with sickle cell disease suffer from various complications during their lifetime. In order to cope with the disease, they must adapt themselves to a complex set of behaviors that promote self-management and prevent complications associated with the disease. Chronic disease self-management programs are a combination of strategies that increase self-efficacy and promote self-management behaviors.

Objectives: This study aimed to determine the effectiveness of self-management programs on self-efficacy in patients with sickle cell disease.

Patients and Methods: In this quasi-experimental study, 69 patients with sickle cell disease who were referred to the Thalassemia Clinic of Ahvaz Shafa Hospital were entered into the study through the census method. Then, the self-management program was implemented using the 5A method for 12 weeks. The Levels of pre and post intervention self-efficacy were assessed using the sickle cell self-efficacy scale (SCSES), while descriptive statistics, paired t-test and Wilcoxon test were used to analyze the data.

Results: Before the intervention, the majority of subjects (50.7%) had moderate self-efficacy, whereas after the intervention, the majority of patients (81.2%) showed high self-efficacy. The overall scores and scores of the post-intervention self-efficacy sub-groups were significantly increased ($P < 0.001$).

Conclusions: The results of this study showed that self-management interventions are effective in promoting self-efficacy in patients with sickle cell disease. Thus, the use of self-management programs is advisable to change behaviors and promote self-efficacy in such patients.

Keywords: Self-Care; Self Efficacy; Anemia, Sickle Cell

1. Background

Sickle cell disease is an inherited blood disorder caused by an inherited gene for sickle hemoglobin (1). It is commonly found in people whose families come from Africa, South or Central America (specifically Panama), Caribbean islands, Mediterranean countries (such as Turkey, Greece, Italy), India and Saudi Arabia. Approximately 2.5 million people in the United States and 300 million people worldwide have the sickle cell trait (2). The disease is found in the southern provinces of Iran, including Sistan and Baluchestan, Hormozgan, Bushehr, Fars, and especially Khuzestan. According to the latest statistics, there are approximately 500 sickle cell patients recorded in the Khuzestan province (3). Patients with sickle cell disease suffer from various complications of the disease during their lifetime, including anemia, sickle cell crises, acute chest syndrome, stroke, renal failure, retinal detachment and priapism (1). However, unforeseen and chronic pain crisis are the most common symptoms reported by the patients (1, 3-5), which are considered as the most common causes of referral to the emergency department and hospital to receive medical care in sickle cell patients (3, 6-8).

Sickle cell disease is a chronic condition that leads to serious health and economic consequences. Evidence asserts that the control of the disease and its complications come at a huge cost. According to assessments, the average cost of treating a sickle cell patient per month is estimated at around 1389 USD; a large part (80.5%) of which is related to the hospitalization of these patients (9). On the other hand, chronic pain, repeated hospitalization and unemployment can lead to lower self-esteem, feeling of frustration (10-12), depression (10), anxiety and stress (11) in these patients. In his study, Anie showed that approximately half of the patients with sickle cell disease suffer from the symptoms of depression as well as feelings of anxiety and self-hatred, and about 40% of patients are unemployed (10). Many studies indicate a low self-efficacy (13-16) and decreased coping skills (17-19) in sickle cell patients. The ultimate goal of treatment for sickle cell patients is disease management and symptom control (20). Patients often experience pain and other health challenges, but how to manage these outcomes can determine their success and efficiency (21). Since the eco-

conomic and social problems caused by unemployments (11) may affect disease interventions, which are based on medical principles, and also because pain caused by sickle cell disease is often managed at home (5), learning strategies to cope with the disease, which warn the pharmaceutical principles, cannot lead to increased skill in dealing with the disease at home and in the community (22). Therefore, these patients need a chance to practice other strategies of their disease management, report the results of their activities and receive feedback (23).

To cope with the disease, people with sickle cell disease must adapt to a complex set of behaviors that promote self-management and prevent complications associated with the disease. Self-care management refers to a process in which the patients have an active role in their health and well-being and is a process involving skills, attitude and abilities required to cope with a chronic disease (24). Self-management programs in chronic diseases are a combination of strategies that enhance self-efficacy and promote self-management behaviors and health outcomes (25). Self-efficacy is also an important prerequisite for successful self-management and behavior changes (26). Self-efficacy is the belief of a person in his/her ability to perform tasks that are associated with daily management of the symptoms and disease (14) and is especially focused on the individual beliefs that can be used to control emotions, behaviors and social environment (27). Self-efficacy is the underlying mechanism that can affect the positive results of self-management programs. As a result, promoting self-efficacy is a key objective for achieving self-management skills (28). A few studies have been conducted on self-efficacy in patients with sickle cell disease showing that self-efficacy can be a determining factor in coping with chronic disease in people (27) and there is evidence indicating that self-efficacy can affect the course of sickle cell disease over time (29). As studies show, fewer physical and psychosocial symptoms are found in sickle cell patients with higher self-efficacy (15, 29, 30), and patients with low self-efficacy reported higher use of health care resources compared with their counterparts who had higher self-efficacy (29). Lenoci et al. also showed a negative relationship between self-efficacy and pain intensity in sickle cell patients (24). The study by Clay and Telfair also showed that adolescents with sickle cell disease who are more engaged in self-care behaviors, such as drinking enough fluids, taking medications, and avoiding too much physical activities reported a higher self-efficacy and lower levels of physical and mental ailments (15). What is important is that self-management interventions should raise the belief and confidence in people (31), because people's belief can motivate them and adjust their behavior and has a significantly important role in changing habits harmful to health (32).

Self-efficacy is a valuable tool for nurses at health centers, and its assessment and promotion can increase motivation among patients (33). Research has shown that there are only sparse studies on self-efficacy in patients with sickle cell disease, and that studies assessing the effectiveness of a com-

prehensive self-management program have rarely been conducted for sickle cell patients. This is completely evident in Iran, therefore, the use of an inexpensive and accessible self-management program seems to be useful and effective to help patients control symptoms and complications of the disease, increase self-satisfaction and sense of well-being, and ultimately improve patient self-efficacy. Such program seems necessary bearing in mind the high prevalence of the disease in the Khuzestan province and the need for controlling this chronic disease, in order to improve quality of life and reduce its undesirable effects among patients and the heavy financial burden on the healthcare system. Also, other factors that emphasize the need of such program are the weakness of traditional education on active participation of patients in their treatment process and the need to support sickle cell patients for behavior changes.

2. Objectives

This study aimed to determine the effectiveness of self-management programs on self-efficacy in patients with sickle cell disease.

3. Patients and Methods

This was a quasi-experimental (one-group before after) study. The research environment was the Thalassemia Ward and Clinic of Shafa Hospital affiliated to the University of Ahvaz. The population of the study consisted of all sickle cell patients over the age of 18 at this center. Due to the small size of the study population, the study samples were based on the study population, therefore, all the patients eligible to enter into the study who expressed their consent to participate in the research were selected as participants. To access the samples, medical records of all the sickle cell patients were extracted. In total 168 individuals who were aged over 18 and had been referred to the Thalassemia Clinic of Ahvaz Shafa Hospital between 2011 and 2013 were included in the study. Some information was provided to the patients about the purpose and outline of the study through a phone call and they were invited to participate in the study. In addition, the researcher attended the clinic for six months from February 2012 to June 2013 and the patients who were referred to the clinic or hospitalized in the ward were invited to participate in the research. Accessing 27 of the patients was not possible due to changes in their contact information and lack of referral to the clinic when the researcher was present. Due to the lack of consent to participate in the study or the absence of the inclusion criteria, 59 patients were not entered into the study. Finally, 82 patients were considered eligible for the study, of which 13 were excluded from the study during the study period due to the lack of participation in the training program. Therefore, the analysis was performed on 69 samples. Inclusion criteria included diagnosis of sickle cell disease by a specialist, age of over 18 years, ability to read and write, having a strong command of the Persian language, residing in the city of Ahvaz or having

the ability to attend the sessions and not suffering from a known mental illness. If the following criteria were identified, participants would be excluded from the study: lack of participation in individual and group training sessions (being absent for one session) and non-compliance with a practical program that was determined at monthly visits.

Method of data collection was based on interviews and a questionnaire completed by the participants. In this research, the data collection instrument consisted of two questionnaires and a behavioral health assessment form (needs assessment). The demographic information questionnaire included items such as age, sex, marital status, level of education, type of sickle cell disease and frequency of hospitalizations due to pain crisis in the previous year. The behavioral health assessment form, which was developed based on authoritative sources (34, 35) using the comments of expert lecturers, was used to examine patient's healthy behaviors, beliefs and knowledge of their disease. The form contained 13 questions that helped the researcher assess the needs, and to set behavioral objectives. The demographic information questionnaire and the behavioral health assessment form were researcher-made. To assess self-efficacy in patients, the sickle cell self-efficacy scale (SCSES) was used. It was designed in 2000 by Edwards et al. to assess self-efficacy in such patients (36). The questionnaire contained nine questions that measured self-efficacy in patients with sickle cell disease, indicating patients' confidence in controlling routines as well as their ability to manage the disease and control pains caused by the disease. The questionnaire was based on a 5-point Likert scale with a score of 1-5 (1 = not at all certain) and (5 = absolutely sure). Scoring was performed as follows: the minimum and maximum scores were 9 and 45, respectively; and scores 9-20, 21-32, and 33-45 indicated low self-efficacy, moderate self-efficacy and high self-efficacy. In this study, the method of face validity was used to determine the scientific validity of the demographic information questionnaire, the behavioral health assessment form, and the self-efficacy scale. In this manner, corrective comments by a group of lecturers and experts were collected and the final questionnaire was developed after revision. The SCSES is a standard tool with a reliability of 0.89, estimated by Edwards et al. in 2000 using the "internal consistency" based on a Cronbach's alpha (36). In this study, the reliability of the self-efficacy scale was also calculated using the Cronbach's alpha coefficient based on a pilot study on 20 patients randomly selected from the study population; the alpha coefficient was estimated at 0.82.

After selecting the patients, written informed consent form approved by the Ethics Committee of Ahvaz University of Medical Sciences was delivered to the patients. When the patients completed the self-efficacy scale and demographic information questionnaire, the study intervention was performed. In this study, we used of a self-management model called the 5A model, developed by Whitlock and Glasgow (37, 38). The program was implemented over a period of 12 weeks including five steps as follows:

3.1. The First Stage (Assess)

Patients' healthy behaviors, beliefs and knowledge of their disease were evaluated by questions using the behavioral health assessment form. In addition, the results of existing experiments were used to examine ways to control the side effects and disease complications. These studies helped the researcher assess needs and set behavioral objectives during the later stages of the model. In fact, at this stage, we conducted interviews and observations to thoroughly evaluate patients' conditions using experimental results.

3.2. The Second Stage (Advise)

At this stage, we used the results of the data analysis obtained from the first stage as the basis for continued intervention; the patients were informed of the abnormalities observed in the experiments and studies, and they were informed about the identified health risks. In addition, the benefits of behavior changes and its relationship with health, the consequences of not controlling the disease and the benefits of disease control were confirmed. Furthermore, the patients were justified in having the skills and abilities needed to succeed in changing their behavior in order to modify the risk factors of the disease.

3.3. The Third Stage (Agree)

During the previous stage, the patients and the health care provider had a written agreement on the performance. Appropriate agreed behavioral objectives (along with a practical program) were developed according to the requirements of each patient based on the studies. This was recorded in the form of behavioral objectives and practical program (34), and a scale of one to ten was presented to the patients for behavioral objectives to determine their level of confidence in the implementation of the program; a fact that raised the enthusiasm of patients and reduced the impact of failure. The patients were then asked to record their status on each of the objectives in their daily record checklists (39) for 12 weeks. In addition, the participants were asked to record cases that cause attacks of pain in their diaries, in order to formulate behavioral objectives in those months. Furthermore, an agreement was made between the health care provider and the patient in relation to their participation in the individual and group counseling sessions and referral for monthly visits. The three steps above were performed in a session of about two hours for each patient in a completely individual manner.

3.4. The Fourth Stage (Assist)

At this stage, we organized an individual training session for the patients who were taught about pain crisis, warning signs and how to relieve pain using home treatment. In these patients, it is necessary to refer to the emergency department, as well as identify and apply cognitive and behavioral techniques to deal with pain (including relaxation, deep breathing, mental imagery and repetition of positive sentences to adapt to pain). We asked the patients

to perform deep breathing and relaxation exercises twice a day, each time for 10 to 15 minutes, and record them in their daily record checklists. This session was held in the second week of the intervention. A group session of 10-15 people was organized during the third week, in which the patients were instructed about the disease, nutrition, physical activities and stress management, with the help of slides and images. The session lasted about four hours. Based on client's needs, small individual and group training sessions were organized for people who had similar problems, in the form of homogeneous groups of 4-3 participants. During these sessions, we taught the required provision of training to the patients. In addition, we discussed successful experiences of similar people regarding pain control or other problems in a purposeful manner, so that the participants could more easily understand the successful experiences of similar people. Furthermore, at this stage, we helped the patients identify barriers of behavior changes as well as strategies to overcome them, while we also taught problem-solving techniques as a central component of an effective self-management. We ensured the patients that we are working to solve their problems and established a friendly interaction between the researcher and the participants. In addition, ample time was spent to answer the questions of patients and adequate feedback was provided. We encouraged the patients when they were comply with the provided guidelines; and taught them necessary issues of each case of failure. Individual sessions lasted almost two hours and the duration of group sessions ranged from two to four hours. In addition, a brochure and a CD containing the training materials presented in training sessions were provided to each patient. The contribution stage continued until the end of the intervention.

3.5. The Fifth Stage (Arrange)

In the follow-up phase lasting 12 weeks, we followed up the patients' progress once a week (if needed, at fewer intervals) by phone. In addition, the telephone number of the researcher was given to the patients, in order to establish a continuous interaction between the researchers and patients. Patients were also visited once a month, to examine the agreed practical programs and related

checklists and if necessary changes in objectives and practical programs were required, further agreements were made. The sessions usually lasted about half an hour.

After the intervention program, all the participants completed the self-efficacy scale and the results were statistically analyzed. To determine the frequency, mean and standard deviation of descriptive statistics, paired t-test and Wilcoxon test were used to compare the total score of self-efficacy and each of the related sub-groups before and after the intervention, respectively. A significance level of $P > 0.05$ was defined. The SPSS v.19 was used to enter and analyze data.

4. Results

Based on the study findings, the average age of participants was 25.84 ± 7.23 . There were 52 female (75.4%) and 17 male (24.6%) participants, including 20 married (29%), 47 single (68.1%), and two divorced (2.9%) patients. The participants included 63.8% patients with sickle cell anemia and 36.2% patients with sickle cell thalassemia. The education levels of the participants in the study were 50.7% below diploma, 34.8% diploma and 14.5% over diploma; and the majority of participants (81.2%) were hospitalized at least once because of pain crisis over the past year.

A comparison between the scores of self-efficacy level in patients with sickle cell disease before and after the intervention indicates that before the intervention, the majority of samples (50.7%) had moderate self-efficacy whereas after the intervention, the majority of patients (81.2%) had high self-efficacy (Table 1). Statistical analysis shows that the average self-efficacy and the mean scores of post-intervention self-efficacy sub-groups increased compared to those before the intervention, and that this increase was statistically significant ($P < 0.001$) (Table 2).

Table 1. Status of Self-Efficacy in Patients With Sickle Cell Disease^a

Status of self-efficacy	Baseline	12 Weeks
Low	23 (33.4)	-
Moderate	35 (50.7)	13 (18.8)
High	11 (15.9)	56 (81.2)
Total	69 (100)	69 (100)

^a Data are presented as No. (%).

Table 2. Comparison Between Changes in Self-Efficacy Before and After the Intervention in Patients With Sickle Cell Disease^a

Components of Self-Efficacy	Baseline	12 Weeks	Z	P Value
Perform activities to reduce pain during periods of pain	2.46 ± 1.05	4.31 ± 0.58	-6.83	$P < 0.001$
Perform most daily activities	3.53 ± 1.11	4.46 ± 0.73	-5.39	$P < 0.001$
Continue to sleep despite pain	1.72 ± 1.02	3.07 ± 1.07	-6.33	$P < 0.001$
Reduce pain using non-pharmacological methods	2.01 ± 1.09	3.78 ± 1.02	-6.22	$P < 0.001$
Control the amount and time of boredom	3.05 ± 1.37	4.08 ± 0.7	-5.12	$P < 0.001$
Overcome the feeling of discomfort and sadness	2.92 ± 1.39	3.85 ± 1.03	-4.40	$P < 0.001$
Manage life	3.31 ± 1.13	4.27 ± 0.78	-5.54	$P < 0.001$
Control the disease symptoms	2.97 ± 1.29	4.23 ± 0.78	-5.97	$P < 0.001$
Cope with failure and disability due to the disease	2.84 ± 1.31	3.95 ± 1	-5.62	$P < 0.001$
Total	24.85 ± 6.76	36.04 ± 4.2	$t = -14.93$	$P < 0.001$

^a Data are presented as mean \pm SD.

5. Discussion

This study aimed to determine the effectiveness of self-management programs on self-efficacy in the patients with sickle cell disease. The results of the study showed that the self-management program had positive impacts on the overall score and self-efficacy sub-groups in the sickle cell patients. The results also indicated that self-efficacy beliefs in patients with sickle cell disease were moderate before the intervention, while the beliefs improved after the intervention. Edward in North Carolina, and Clay, Jeneret, Adegbola in the United States reported that the mean score of self-efficacy in patients with sickle cell disease was nearly equal to the average score (13-15, 29). Cashaw also performed a single-group quasi-experimental study to evaluate the effectiveness of a self-management program based on behavioral interventions, with the aim of improving nutrition among adolescents with sickle cell disease, aged 13-17 years in Philadelphia. The results showed that the self-efficacy beliefs of all the participants were moderate before the intervention and improved after the intervention (30).

A similar study conducted in Philadelphia on adolescents with sickle cell disease, in which techniques of coping with pain (pain management) and educating patients (self-management) were used for both groups during four sessions (three sessions during two weeks and a recalling session in the later month). The results of the study showed that although the mean scores of self-efficacy in the patients increased in both groups after the intervention and the follow-up performed a year later, the difference was not significant (28). The difference between the results of our study and that mentioned above may be attributed to the small sample size of the abovementioned study, in which 17 and 20 patients remained in both groups, as compared with a larger sample size in our study. However, researchers of the abovementioned study reported that basic interventions, which encompass a broader range of skills relating to disease management and health information, might be more effective (23). The results of this study confirm the findings of a study by President et al. according to which a comprehensive self-management program that is a combination of pain management and disease education can be effective in promoting self-efficacy in patients with sickle cell disease.

The results of our study are consistent with another study carried out by Hewlett et al. in 2011 on patients with rheumatoid arthritis. Sickle cell disease and rheumatoid arthritis are two chronic diseases that are characterized by pain, sleep disorders, boredom, frustration and depression, and should benefit from self-management programs. In this study, self-management interventions that were done based on cognitive behavioral therapies had been effective in increasing self-efficacy in patients with rheumatoid arthritis. These interventions also had an impact on the resultants such as sleep, depression, frustration and boredom in these patients (40). The results of a study by Baljani et al. showed that interventions to pro-

mote self-efficacy had a positive impact on the total scores and self-efficacy sub-groups in patients with heart failure (33). The implementation of a self-management program on self-efficacy related to pain in patients with neck pain has also been shown to be effective in the study of Gustavsson et al. (41). In addition, the study of George et al. showed that the implementation of education-based self-management programs about psychological care and disease is effective in promoting self-efficacy in patients with type 1 diabetes (42). Lomundal et al. demonstrated the effectiveness of the self-management program in promoting self-efficacy in patients with chronic respiratory failure (43). Williams et al. also conducted a self-management program based on the self-efficacy theory and based on individual and group sessions for patients with chronic diseases. The results indicated that, although no significant difference was found in self-efficacy between intervention and control groups, average self-efficacy improved in the intervention group from baseline to 16 weeks of study after the intervention, and this difference was reported to be significant ($P = 0.02$) (44), which is consistent with the results of our study.

Some studies have also failed to demonstrate the effectiveness of self-management programs on self-efficacy. For example, a study was conducted by Hamnes et al. for four weeks (one week of intervention and three weeks of follow-up) to determine the effectiveness of self-management programs on patients with fibromyalgia syndrome, myalgia; the results showed that the program had no effect on the self-efficacy in these patients. According to the above study, the weaknesses were due to the intensive intervention period and the lack of attention paid to the needs of participants during intervention planning and to the creation of motivation in these patients (45). However, needs assessment and evaluation of patients' problems are the main steps of the 5A model, and the agreement stage is one of the unique features of this model, in which the patients are actively involved in developing their self-management program; this is highly effective in motivating patients and inspiring enthusiasm for a more active participation. Tanabe et al. believe that patient-centered care, in which the patient's independence is supported, and participatory decision-making are associated with better self-management and the promotion of self-efficacy in chronic patients, especially sickle cell patients (46). In addition, studies have shown that sharing experiences is an important factor in the success of self-management (47), and factors such as poor communication with the health care provider and lack of knowledge are the barriers to the success of a self-management program (48). Therefore, in the contribution stage of this study, we tried to enter the participants into purposeful discussions in order for them to share their successful experiences. On the other hand, maintaining a good and constant interaction between the health care provider and the clients and providing the patients with necessary knowledge could be beneficial and help patients gain

control over the disease. Effort to improve the level of the patient's consciousness is another strength of this study. Consciousness is the most important component of self-management, which includes awareness of specific behaviors that lead to health promotion (46). In this study, the participants were asked to record events that cause attacks of pain in their diaries and deliver the diaries to the researcher. This was a key turning point in the lives of the participants, because they began to take control of their disease through these diaries. Due to the limited study population and inability to provide a match for the study group, the study was conducted as a one-group before and after without having a control group, therefore the generalizability of the results is affected. On the other hand, since education pamphlets and instruction with a power point were used in the disease education, we only selected patients with early literacy. Consequently, the results may not be generalized for illiterate patients.

Self-management programs for sickle cell patients have received little attention. However, various studies show that if a self-management program is designed based on the needs of patients, it can be effective for motivating patients to change behavior and thus promote self-efficacy in chronic patients. In this study, some characteristics of the intervention used in the study also appeared to be effective in promoting self-efficacy in patients with sickle cell disease. This included detailed and comprehensive evaluation, personal face-to-face training, individual consultations and group discussions to share experiences, agreement with the patient about behavioral objectives and completion of checklists for a practical program, ongoing communication with the patient and the necessary changes in practical programs to achieve the behavioral objectives.

The main objective of clinical nursing is to help improve patients' health. Self-management is an important element in improving chronic diseases. The results of this study indicated that using the 5A model, self-efficacy in patients could be improved. Furthermore, the results of other studies showed that improper training structures are found in medical centers to promote self-management behaviors in chronic patients (49). Therefore use of the 5A model is suggested as an easy option for nurses in Iran to reduce the symptoms of patients, because it is low-cost, easy-to-find and can create motivation by involving patients in self-care. However, the findings of this study should be generalized to other sickle cell patients and other situations with caution. Therefore, it is recommended to perform this research as a clinical trial on other populations and evaluate the effectiveness of this model during a longer period of time.

Authors' Contributions

MA devised the concept for the study, developed the study design, collected data, ran the study intervention, was involved in the conception of the study, and performed the analyses and final preparation of the manuscript. ASH supervised data collection and analysis, contributed to the study design and intervention. SJ supervised data collection and analysis and was involved in study coordination and manuscript revision. HT developed the study design, performed the analyses. BK assisted in data gathering. All authors read and approved the final manuscript.

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