The Effectiveness of Self Management Program on Pain, Fatigue, Depression, Anxiety, and Stress in Sickle Cell Patients: A Quasi-Experimental Study

Mehrnaz Ahmadi,1 Abdolali Shariati,1 Saeed Poormansouri,2* and Najva Hazeghi3

1Department of Nursing, Nursing and Midwifery School, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, IR Iran
2Supervisory Office, Treatment Deputy, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, IR Iran
3Midwifery Department, Reproductive Health Promotion Research Center, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, IR Iran

*Corresponding author: Saeed Poormansouri, Supervisory Office, Treatment Deputy, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, IR Iran. Tel: +98-665187081, Fax: +98-6133375690. E-mail: Mer.ahmadi@gmail.com

Received: April 29, 2015; Revised: May 20, 2015; Accepted: June 4, 2015

1. Background

Sickle cell disease (SCD) is the most common genetic disorder of hemoglobin worldwide (1). The disease is characterized by painful crises due to obstruction of blood vessels (2); it affects around 100,000 people in the United States and is one of the most common genetic diseases in United States (3). This disease is found in the southern provinces of Iran, especially in Khuzestan; there are approximately 500 sickle cell (SC) patients in this province (4). Occlusive episodes cause complications characteristically associated with SCD such as pain, stroke, aplastic crisis, severe hemolytic anemia, acute chest syndrome, and chronic damage to organs (5); however, pain in the abdomen, chest, lower back, and joints are the most common problems reported by SC patients (6), which are considered the most common causes of referral to emergency departments (3, 4, 6).

In managing serious and unpredictable complications, patients with SCD suffer numerous psychosocial problems such as reduced self-esteem, feelings of frustration (7), depression (7-9), anxiety and stress (8), and disruption of interpersonal relationships (10); these often lead to fatigue (11-14) and poor quality of life (13, 15-17) in these patients. Bakri et al. (10) showed that depression, anxiety and stress are prevalent in SC patients compared with healthy subjects. Sogutlu et al. (18) also showed that 60% and 37.5% of patients with SCD experience significant anxiety and depression, respectively. Many studies indicate that SC patients have decreased coping skills (19, 20). By contrast, in SCD, the pathophysiology of the disease process (e.g. severe hemolytic anemia and unforeseen vascular occlusion crises) indicates that patients with SC may be at risk of acute and chronic fatigue (14). Additionally, studies have shown that fatigue may reduce patients’ ability to perform daily activities (13, 17). Dampier et al. (13, 17) found that adolescents with SCD reported lower levels of sleep and rest, and elevated fatigue, compared to healthy peers; another study found that young adults with SCD reported lower levels of energy than the general population.

Keywords: Self-management; Pain; Fatigue; Anxiety; Depression; Stress; Sickle Cell
The main characteristic of SCD is pain (5). Extant research indicates a relationship between pain, fatigue, depression, anxiety, and stress in SCD patients (12). Severe pain in SC patients has been associated with reduced vitality, increased fatigue (11, 13) and increased prevalence of depression, anxiety, and stress (3, 21, 22). Dampier et al. (13) demonstrated a significant relationship between pain and fatigue in SC patients. Other studies have shown that the prevalence of depression in SC patients is associated with sleep disturbance, poor adherence to treatment, and daily pain (3). Anxiety has been reported as a factor contributing to the frequency and severity of pain in SC patients, as well as reinforcing the pain state and stress; anxiety has also been identified as a precipitating factor in the onset of pain crises (21, 22).

In the biobehavioral model of pain, many variables, in addition to disease severity, influence pain perception. A group of these factors is related to the family environment and social support; however, other factors are related to patients’ functional status, pain management ability, and psychological adjustment (23). SC patients therefore are benefited by learning how to manage their disease in order to overcome pain, fatigue, depression, anxiety, and stress caused by the disease, and achieving an acceptable level of quality of life (24). Studies have emphasized the positive role of self-management and pain-management in SCD support in ameliorating physical and psychological problems (20, 21, 23). Self-management programs are designed to help patients determine their needs and problems, and to assist them to overcome these (25). Although there is evidence indicating that self-management improves health outcomes in SC patients and patients with other chronic diseases (25-28), little research has examined the implementation of such programs in reduction of pain, fatigue, depression, anxiety, and stress in patients with SCD.

2. Objectives

The aim of this study was to determine the effectiveness of self-management programs on SC patients’ pain, fatigue, depression, anxiety, and stress.

3. Patients and Methods

This research ran a quasi-experimental (one-group pre-post) study performed at the Thalassemia Clinic of Shafa Hospital affiliated with the Ahvaz Jundishapur University of Medical Sciences, Khuzestan, Iran. Recruitment criteria included all people with SCD or sickle thalassemia aged over 18 years (due to the limited study population, the sample used the entire patient population). Eligible participants were able to read and write, had a strong understanding of the Persian language, resided in the city of Ahvaz or were able to attend the sessions, and did not suffer from a known mental illness. Participants were excluded from the study in case of lack of participation in individual or group training sessions (i.e. absence for one session) and in case of non-compliance with a practical program determined at monthly visits.

To access the samples, medical records of all participants were extracted. In total, 168 individuals aged over 18 years had been referred to the Thalassemia Clinic of Ahvaz Shafa Hospital between 2011 and 2013; these were included in the study. Information was provided to participants about the purpose and outline of the study via phone call; participants were subsequently invited to participate in the study. For better access to the patient population, the researcher attended the clinic for six months from February 2012 to June 2013; patients referring to the clinic were invited to participate in the research. Accessing 27 of the patients was not possible due to changes in their contact information or referral to the clinic while the researcher was absent. Due to lack of consent to participate in the study, or failure to meet the inclusion criteria, 59 patients were excluded. Finally, 82 patients were considered eligible for participation, of which 13 were excluded during the study period due to lack of participation in the training program; 16 further participants dropped out before follow-up. The analysis was therefore performed on 53 participants.

3.1. Questionnaire

In this research, data collection instruments were a demographic information questionnaire, fatigue severity scale (FSS), depression anxiety stress scale 21 (DASS21), and a pain record form. The demographic information questionnaire consisted of eight questions examining age, sex, marital status, level of education, type of sickle cell disease, ethnicity, occupation, and the number of hospitalizations due to pain crisis in the previous year. The FSS is a self-report measure designed to assess disabling fatigue in any individual (29). The FSS, which consists of nine questions, uses a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The total score on the FSS is calculated as the average of the individual item responses. Those with a score of 36 and higher were considered to have symptoms of fatigue; those with scores less than 36 were considered to have no signs of fatigue (30). The FSS has been supported as a valid and reliable scale, and was standardized by Shahvarughi et al. (31) in Iran. The DASS21 is a 21-item self-report questionnaire designed to measure the severity of a range of symptoms common to depression, anxiety and stress. In completing the DASS, the individual is required to indicate the presence of each symptom over the previous week. Each item is scored from 0 (never) to 3 (almost always). The total score is the sum of each subscale’s score. Defined cutoff points are as follows: regarding depression, a score of 0 - 4 is regarded as normal, 5 - 6 as mild, 7 - 10 as moderate, 11 - 13 as severe, and 14 or higher as extremely severe. Regarding anxiety, a score of 0 - 3 is regarded as normal, 4 - 5 as mild, 6 - 7 as moderate, 8 - 9 as severe, and 10 or higher as extremely severe. Regarding stress, a score of 0 - 7 is regarded as normal, 8 - 9 as
mild, 10-12 as moderate, 13-16 as severe, and 17 or higher as extremely severe. The DASS 21 was developed and validated by Lovibond and Lovibond (32). The questionnaire’s validity and reliability has been supported by Sahebi et al. (33) in Iran. In this study, the reliability of the FSS and DASS 21 in SC patients was analyzed using Cronbach’s α; based on a pilot study on 20 patients who were randomly selected from the population, reliability was estimated at 0.78 and 0.89 for the FSS and DASS 21, respectively. Participants completed the questionnaires before and after the intervention. A record form was used to examine frequency and duration of pain; patients recorded pain frequency and the beginning and end of each period of pain. (Participants completed nine record forms during the 36 weeks of assessment).

After patient recruitment, participants supplied written informed consent. After participants had completed the questionnaires, the self-management program was administered in five sessions for 12 weeks. Sessions were organized as follows: two individual sessions in the first and second week, a large group training session (10 - 15 persons) in the third week, two small group training sessions (3 - 4 persons), and several individual and small group sessions based on patients’ needs from the fourth until the twelfth week of the intervention. Individual sessions lasted slightly less than two hours; group sessions lasted from two to four hours.

In the first individual session, participants’ level of awareness, understanding, and performance expectations were evaluated by interview using a needs assessment form. The needs assessment form, which was developed following the comments of expert lecturers, contained 13 questions that helped the researchers to assess participants’ needs and set behavioral objectives. Also at this stage, participants were asked to express their priorities for changes in their lives. Subsequently, appropriate mutually agreed behavioral objectives (as well as a practical program) were developed according to the requirements of each participant based on participants’ identified needs and priorities. This was recorded in the form of behavioral objectives and the practical program. Participants were then asked to record their status regarding each of the objectives in their daily record checklist for 12 weeks. Additionally, participants were asked to record cases that caused attacks of pain, and the frequency and duration of pain, in the pain record form, in order to formulate behavioral objectives in those months. Further, an agreement was made between the health care provider and the participant regarding the participant’s engagement in individual and group counseling sessions and referral for monthly visits.

In the second individual session, an individual training session was organized for each participant in which the participant was individually taught about pain crises, and how to relieve pain using home treatment (massage, the use of liquids, hot showers, etc.), as well as cognitive and behavioral techniques for pain management (e.g. relaxation, deep breathing, distraction techniques, such as mental imagery, and repeating positive phrases to adapt to pain). Participants were asked to perform deep breathing and relaxation exercises twice a day, for 10 - 15 minutes each time. Additionally, participants were taught about the benefits of daily exercise and a balance between activity and rest, and were asked to perform 20 - 30 minutes of walking or cycling, and record these in their daily record checklists.

In group sessions, participants were informed regarding the disease and its management using slides and images. Additionally, this session included discussion of strategies to improve sleep, as well as discussion regarding depression, anxiety, and stress management techniques. Small group training sessions and other sessions were administered from the fourth until the twelfth week of the intervention; these provided further training to participants. Moreover, participants were asked to discuss instances in which they had succeeded in controlling their pain or other problems, to permit participants to adopt one another’s successful management strategies. At this stage, participants were taught problem solving techniques, were helped to identify barriers to behavior change, and were acquainted with overcoming these barriers.

In this study, participants were followed for 36 weeks in two phases over a period of 12 weeks (intervention period) and 24 weeks (follow-up after intervention). During the first 12 weeks, participants’ progress was checked by telephone once a week. To establish continuous interaction, the researcher’s telephone number was provided to participants. Participants were also visited every four weeks. During the monthly visit sessions, which lasted around half an hour, practical programs and related checklists were examined, and necessary changes in objectives and practical programs were made upon a further agreement. In the 24 week post-intervention follow-up, participants were contacted monthly by telephone to gather feedback on training, and provide necessary instruction. Whenever an unplanned visit was required, the researcher was present at the clinic.

3.2. Ethical Considerations

After obtaining permission from the research council and the ethical committee of the researcher’s university (Ethic Code ETH-739), the current study was conducted after coordination with the authorities of the Ahvaz Shafa Hospital and Thalassemia Clinic. Participants were briefed regarding participation requirements, confidentiality, and inappropriate use of information, as well as the study’s objective, before completing the initial questionnaire; written consent was then obtained for inclusion. Participants were assured of the right to withdraw anytime during the study period, and that they would not incur any additional cost. The current study was part of a research project approved by Ahvaz Jundishapur University of Medical Sciences, Iran, No. 92030.
3.3. Statistics

SPSS 19.0 was used for data analysis. Data were analyzed using descriptive statistics, Fisher’s exact test, Chi-square, independent t-tests, paired t-tests, repeated measures tests, and correlations. A significance level of $P \leq 0.05$ was defined.

4. Results

The average age of participants was $25.98 \pm 7.18$; 36 participants were women (67.9%) and 17 were men (32.1%). Other demographic information is shown in Table 1, which also compares participants’ demographic characteristics (final sample and dropouts). Except for frequency of hospitalizations in the past year, no significant differences were observed in between the two groups’ demographics. Additionally, scores before the intervention regarding fatigue, depression, anxiety, and stress in the final sample and among dropouts were compared using an independent t-test. The result showed a significant difference between scores for fatigue; participants who dropped out reported more fatigue. Participants who had been hospitalized several times in the past year, and those who reported more fatigue, seemed to have less incentive to participate in training sessions and to follow self-management programs. Regarding other comparisons, differences were not statistically significant (Table 1).

Table 1. Baseline Demographic and Clinical Characteristics, and Comparison of Mean Scores for Fatigue, Depression, Anxiety, and Stress: Final Sample and Dropouts *

| Variable                                      | Final Sample (n = 53) | Dropouts (n = 29) | P Value |
|-----------------------------------------------|----------------------|-------------------|---------|
| Age, y                                        | 25.98 ± 7.18         | 26.68 ± 7.6       | 0.67 b  |
| Gender                                        |                      |                   |         |
| Male                                          | 17 (32.1)            | 11 (37.9)         | 0.63 c  |
| Female                                        | 36 (67.9)            | 18 (62.1)         |         |
| Marital status                                |                      |                   | 0.26 d  |
| Married                                       | 37 (69.8)            | 16 (55.2)         |         |
| Single                                        | 15 (28.3)            | 13 (44.8)         |         |
| Divorced                                      | 1 (1.9)              | 0 (0)             |         |
| Education                                     |                      |                   | 0.58 d  |
| Less than high school                         | 26 (49.1)            | 17 (58.6)         |         |
| High school diploma                          | 20 (37.7)            | 10 (34.5)         |         |
| College                                       | 7 (13.2)             | 2 (6.9)           |         |
| Sickle cell disease genotype                  |                      |                   | 0.42 c  |
| HbSS                                          | 34 (64.2)            | 20 (69)           |         |
| Sickle beta thalasemia                        | 19 (35.8)            | 9 (31)            |         |
| Frequency of hospitalizations in the past year|                      |                   | 0.007 c |
| No admission                                  | 11 (20.8)            | 0 (0)             |         |
| Have been hospitalized at least once          | 42 (79.2)            | 29 (100)          |         |
| Occupation                                    |                      |                   | 0.82 d  |
| Employed                                      | 11 (20.7)            | 7 (24.1)          |         |
| Unemployed                                    | 32 (60.4)            | 18 (62.1)         |         |
| Student                                       | 10 (18.9)            | 4 (13.8)          |         |
| Fatigue                                       | 36.47 ± 13.33        | 44.86 ± 11.79     | 0.006 b |
| Depression                                    | 9.13 ± 5.71          | 8.65 ± 5.12       | 0.7 b   |
| Anxiety                                       | 9 ± 4.54             | 8.31 ± 4.34       | 0.5 b   |
| Stress                                        | 12.39 ± 4.93         | 12.27 ± 4.53      | 0.91 b  |

* Data are presented as No. (%) or mean ± SD.

Jundishapur J Chronic Dis Care. 2015;4(4):e29521
The results indicated that fatigue was significantly positively correlated with depression ($P < 0.001, r = 0.44$), anxiety ($P = 0.008, r = 0.31$), and stress ($P = 0.003, r = 0.34$) before the intervention, and that the frequency of pain during the total study period was significantly positively correlated with depression ($P = 0.01, r = 0.33$), anxiety ($P = 0.002, r = 0.4$), and stress ($P = 0.02, r = 0.3$) in patients at the end of the study period; however, no significant relationship was found between fatigue and pain frequency.Duration of pain was found to be significantly related to depression ($P = 0.006, r = 0.36$), anxiety ($P = 0.02, r = 0.31$), and fatigue ($P = 0.02, r = 0.31$); however, no significant relationship was found between stress and duration of pain.

Analysis of rates of depression, anxiety, stress, and fatigue is shown in Table 2. The results indicate that the majority of participants suffered from depression, anxiety, stress, and fatigue associated with the disease before the intervention, while after intervention the majority of participants scored normally for depression, anxiety, stress, and fatigue.

Comparisons between depression, anxiety, stress, and fatigue scores before and after the intervention indicated that mean scores for depression, anxiety, stress, and fatigue after the intervention were lower than those collected before the intervention; a paired t-test indicated a significant difference ($P < 0.05$).

An ANOVA with repeated measures indicated that mean score for frequency and duration of pain decreased significantly during the 12 weeks of intervention, as well as during the 24 weeks of follow-up ($P < 0.001$) (Table 3).

| Variable | Score | Baseline | 36 Weeks | P Value |
|----------|-------|----------|----------|---------|
|          |       | Number (%) | Mean ± SD | Number (%) | Mean ± SD |
| **Depression** | | 9.13 ± 5.71 | 3.92 ± 4.03 | < 0.001 |
| Normal | 0 - 4 | 20 (37.7) | 36 (67.9) |
| Mild | 5 - 6 | 3 (5.7) | 5 (9.4) |
| Moderate | 7 - 10 | 3 (5.7) | 8 (15.1) |
| Severe | 11 - 21 | 27 (50.9) | 4 (7.9) |
| **Anxiety** | | 9 ± 4.54 | 4.47 ± 3.29 | < 0.001 |
| Normal | 0 - 3 | 4 (7.5) | 27 (50.9) |
| Mild | 4 - 5 | 10 (18.9) | 9 (17) |
| Moderate | 6 - 7 | 10 (18.9) | 7 (13.2) |
| Severe | 8 - 21 | 29 (54.7) | 10 (18.9) |
| **Stress** | | 12.39 ± 4.93 | 7.15 ± 4.61 | < 0.001 |
| Normal | 0 - 7 | 9 (17) | 27 (50.9) |
| Mild | 8 - 9 | 4 (7.5) | 8 (15.1) |
| Moderate | 10 - 12 | 14 (26.4) | 10 (18.9) |
| Severe | 13 - 21 | 26 (49.1) | 8 (15.1) |
| **Fatigue** | | 36.47 ± 13.33 | 18.5 ± 13.19 | < 0.001 |
| No signs of fatigue | < 36 | 23 (43.4) | 47 (88.7) |
| Signs of fatigue | > 36 | 30 (56.6) | 6 (11.3) |

| Variable | First 4 Weeks | Second 4 Weeks | Third 4 Weeks | P Value | First 12 Weeks | Second 12 Weeks | Third 12 Weeks | P Value |
|----------|---------------|----------------|---------------|---------|----------------|----------------|----------------|---------|
| Frequency of pain | 4.47 ± 0.29 | 3.24 ± 1.80 | 2.39 ± 1.84 | < 0.001 | 10.11 ± 5.39 | 8.64 ± 5.21 | 8.81 ± 5.2 | < 0.001 |
| Duration of pain, h | 57.47 ± 32.06 | 46.98 ± 27.74 | 34.26 ± 27.08 | < 0.001 | 138.71 ± 83.55 | 126.26 ± 81.54 | 133.01 ± 80.21 | < 0.001 |

*Data are presented as mean ± SD.*
5. Discussion

The purpose of this study was to determine the effect of self-management programs on pain, fatigue, depression, anxiety, and stress in SC patients. Patients with SCD experience multiple disease-related complications; the physical, psychological, and social effects of these expose these patients to an evaluated risk of acute and chronic fatigue (12), as well as depression, anxiety, stress, and other mental health problems (3, 6).

This study’s findings indicate that fatigue is significantly related to depression, anxiety, and stress; that pain frequency during the study period was significantly related to depression, anxiety, and stress; and that duration of pain was significantly related to depression, anxiety, and fatigue. These relationships may be due to the burdensome nature of the disease; unforeseen and chronic pain crises may lead to fatigue, depression, anxiety, and stress. Extant research has found that adolescents and young adults with SCD suffer from mild to moderate fatigue, and that high levels of fatigue are associated with increased depression, anxiety, stress, sleep disorder, chronic pain, and loss of activities of daily life and quality of life (11, 34). Other research has found a relationship between pain and psychiatric disorder, and has demonstrated that reduced pain is associated with significant improvements in general health, quality of life, and mood disorder in SC patients (3, 15). Bakri et al. (10) found that patients with SCD and who had history of repeated hospitalization are at an increased risk of developing behavioral problems and psychiatric disorders, including depression and anxiety. That study reported that psychological counseling, social support, and proper pain management may minimize these consequences. Many other studies have emphasized the ability of disease and pain management to reduce the level of mental disorder and improve quality of life in these patients (15, 20, 21).

The current study’s results indicate that mean depression, anxiety, stress, and fatigue scores in SC patients were significantly elevated, and that these scores were significantly improved after administration of the self-management program. Some of the characteristics of the intervention also appeared to be effective in reducing scores on these variables in patients with SCD, specifically, detailed evaluation of patients, design of self-management programs based on each patient’s needs, personal face to face training, individual and group consultations, pain management training, and management strategy training for stress, depression, anxiety, and fatigue.

Although several studies have examined the implementation of self-management programs targeting sickle cell patients, these studies’ results are not comparable with those of the present study, excepting a study conducted by Anie (35), which is similar to this study regarding behavioral interventions. That study, which used a quasi-experimental (one-group pre-post) design, showed a decrease in scores for depression, anxiety, and frequency and duration of pain after the intervention’s implementation, which is consistent with the results of the present study; however, significant differences between pre- and post-intervention scores were confined to anxiety. This difference in results may be due to a smaller sample size relative to the current study. Provided training was the same for all patients in that study, however; unlike the present study, it did not provide needs assessment and goal-setting based on patients’ needs, a significant number of individual and group sessions on pain management, or group discussions for experience sharing. Previous studies have found that patient-centered care, participatory decision-making (36), and group discussions for experience sharing (37) are associated with better self-management in sickle cell patients.

Regarding other research, Thomas carried out a randomized clinical trial to assess the effects of therapeutic touch with music on stress, anxiety, and pain (compared with a music therapy group) in patients with SCD. That study’s results indicated a significant difference between the intervention and control groups regarding reduction in pain; however, no significant differences were observed between the two groups regarding stress and anxiety. That study’s results nonetheless showed a significant reduction in anxiety in the control (music therapy) group, and reduction of stress in both groups, which is consistent with our results (22). Further, several studies have reported the effectiveness of self-management programs on depression and anxiety in patients with chronic disease (38, 39).

Limited research has examined fatigue in patients with SCD, particularly regarding active patient involvement in fatigue improvement; however, many studies have demonstrated the effectiveness of self-management programs on fatigue in patients with chronic disease. For example, Hewlett et al. (40) who examined patients with rheumatoid arthritis, found results consistent with those of our study. Sickle cell disease and rheumatoid arthritis are both chronic diseases that are characterized by pain, fatigue, frustration, depression, and anxiety, and which may benefit from self-management programs. Hewlett et al.’s (40) results showed decreased fatigue, depression, anxiety, sleep, and frustration scores after a self-management interventions’ implementation. Further, the results of studies examining fatigue in cancer patients (41), patients with chronic fatigue (42), women with metastatic breast cancer (38), and patients with multiple sclerosis (43) indicate the effectiveness of self-management programs on fatigue, which is consistent with the results of the present study.

Some studies have failed to demonstrate the effectiveness of self-management programs on fatigue. For example, Rietberg et al. (44) who examined multiple sclerosis, found that an administered program had no effect on fatigue in those patients. The difference in results between that and the present study may be due to differing
5.1. Limitations and Recommendations

As the present study included no control group, the obtained findings are not definitive; further research using well-designed randomized control trials and evaluation of the long-term effects of similar programs is therefore recommended. Further, the psychological state of participants may have affected their responses, potentially limiting data validity. Controlling for these limitations was difficult. Additionally, self-report measures were used for final data collection regarding pain frequency and duration; the accuracy of that data must therefore be considered potentially limiting.

Acknowledgements

This paper was supported by Ahvaz Jundishapur University of Medical Sciences. We hereby thank the vice-chancellor of Ahvaz Jundishapur University of Medical Sciences for provided financial support, as well as all patients who participated in this study.

Authors’ Contributions

Mehrnaz Ahmadi devised the concept for the study, developed the study design, collected data, ran the study intervention, and was involved in the conception of the study, data analysis, and the final preparation of the manuscript; Abdolali Shariati supervised data collection and analysis, and contributed to the study design and intervention; Saeed Poormansouri supervised data collection and analysis, and was involved in study coordination and manuscript revision; Najva Hazeghi was involved in manuscript revision.

Funding/Support

This study was conducted with financial support from the Ahvaz University of Medical Sciences, Ahvaz, IR Iran.
by internalizing symptoms and parenting stress. Health Qual Life Outcomes. 2008;6:50.
24. Jenerette CM, Murdaugh C. Testing the Theory of Self-care Management for sickle cell disease. Res Nurs Health. 2008;31(4):355–69.
25. Farrell K. Chronic disease self management program (CDMP) impacts perceived health status for underserved rural clients. Southern on line j nurs res. 2008;8(3):11–16.
26. Ahmadi M, Jahani S, Poormansouri S, Shariati A, Tabesh H. The Effectiveness of self management program on quality of life in patients with sickle cell disease. Iran J Ped Hematol Oncol. 2015;3(1):28–26.
27. Ritter PL, Lee J, Lorig K. Moderators of chronic disease self-management programs: who benefits? Chronic Illn. 2011;7(2):162–72.
28. Ahmadi M, Shariati A, Jahani S, Tabesh H, Keikhaei B. The effectiveness of self-management programs on self-efficacy in patients with sickle cell disease. Jundishapur J Chronic Dis Care. 2014;3(1):1–7.
29. Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. Arch Neurol. 1989;46(10):1121–3.
30. Dehghan A, Ghaem H, Borhani Haghighi A, Khashi SM, Zeyghami B. Comparison of quality of life in Parkinson's patients with and without fatigue. Bimonth J Hormozgan Univ Med Sci. 2013(5):49–55.
31. Shahvarughi Farahani A, Azimian M, Fallahpour M, Karimlou M. Evaluation of Reliability and Validity of the Persian Version of Fatigue Severity Scale (FSS) among Persons with Multiple Sclerosis [in persian]. Quart J Rehabil. 2013;3(4):84–91.
32. Lovibond PF, Lovibond SH. The structure of negative emotional states: comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. Behav Res Ther. 1995;33(3):335–43.
33. Sahebi A, Asghari A, Salari RS. Validation of depression anxiety and stress scale for an Iranian population [in persian]. J Iranian psychol. 2005;3(4):299–312.
34. Bazen P. Cognitive Appraisal of Pain and Other* Chronic Stressors in Adults Living with Sickle Cell Disease (SCD): Correlates and Predictors of Emotional and Quality of Life Outcomes. New York: University of Rochester; 2011.
35. Anie KA, Green J, Tata P, Fotopoulos CE, Oni L, Davies SC. Self-Help Manual-Assisted Cognitive Behavioural Therapy for Sickle Cell Disease. Behav Cogn Psychother. 2002;30(4):351–8.
36. Tanabe P, Porter J, Creary M, Kirkwood J, Miller S, Ahmed-Williams E, et al. A qualitative analysis of best self-management practices: sickle cell disease. J Natl Med Assoc. 2010;102(11):1303–4.
37. Hamnes B, Hauge ML, Kjeken I, Hagen KB. ‘I have come here to learn how to cope with my illness, not to be cured’: a qualitative study of patient expectations prior to a one-week self-management programme. Musculoskeletal Care. 2011;9(4):200–10.
38. Eyles C, Leydon GM, Hoffman CJ, Copson ER, Prescott P, Chorozoglou M, et al. Mindfulness for the self-management of fatigue, anxiety, and depression in women with metastatic breast cancer: a mixed methods feasibility study. Integr Cancer Ther. 2013;12(4):42–56.
39. Deechakawan W, Heitkemper MM, Cain KC, Burr RL, Jarrett ME. Anxiety, depression, and catecholamine levels after self-management intervention in irritable bowel syndrome. Gastroenterol Nurs. 2014;37(1):24–32.
40. Hewlett S, Ambler N, Almeida C, Cliss A, Hammond A, Kitchen K, et al. Self-management of fatigue in rheumatoid arthritis: a randomised controlled trial of group cognitive-behavioural therapy. Ann Rheum Dis. 2011;70(6):1060–7.
41. Gracey JH, Watson M, Payne C, Rankin J, Dunwoody L. Translation research: ‘Back on Track’, a multiprofessional rehabilitation service for cancer-related fatigue. BMJ Support Palliat Care. 2014.
42. Meng H, Friedberg F, Castora-Binkley M. Cost-effectiveness of chronic fatigue self-management versus usual care: a pilot randomized controlled trial. BMC Fam Pract. 2014;15:384.
43. Thomas PW, Thomas S, Kersten P, Jones R, Slingsby V, Nock A, et al. One year follow-up of a pragmatic multi-centre randomised controlled trial of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. BMC Neurol. 2014;14:109.
44. Rietberg MB, van Wegen EE, Eysens IC, Kwakkel GMS. Study group. Effects of multidisciplinary rehabilitation on chronic fatigue in multiple sclerosis: a randomized controlled trial. PLoS One. 2014;9(9):e107700.