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Research Paper

Effect of empowerment-based interventions on self-efficacy and selfcare capacity among patients with sickle cell disease: A randomized controlled trial



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ABSTRACT

Objective: This study aimed to investigate the effect of empowerment-based interventions on self-efficacy and self-care capacity among adults with sickle cell disease (SCD).

Methods: A randomized control trial was conducted [NCT06296654]. A total of 76 patients were recruited by using a cluster sampling technique in the two health centers in Bahrain from February to May 2022 and randomly allocated to the intervention group (n = 38) or control group (n = 38). The intervention group received the empowerment-based intervention implemented through structured small-group discussion sessions, individualized consultations (5A model: assess, advise, agree, assist, and arrange), and follow-up sessions, while the control group received routine health education. The Sickle Cell Self-Efficacy Scale (SCSES) and the Appraisal of the Self-Care Agency Scale-Revised (ASA-R) were measured at baseline and one month after the intervention among two groups of patients.

Results: A total of 68 patients completed the study (36 patients in the intervention group and 32 patients in the control group). After the intervention, the score of SCSES in the intervention group was 37.0 (35.0, 39.8) higher than the control group 28.0 (25.2, 32.0) (U = -6.121, P < 0.001); the score of ASA-R in the intervention group was 61.0 (58.3, 65.0) higher than the control group 49.0 (43.3, 53.0) (U = 0.653, P < 0.001).

Conclusion: Adopting the empowerment-based intervention using the 5As model effectively improves self-efficacy and self-care capacity among patients with SCD.

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What is known?

• Literature shows that the chronic nature of sickle cell disease (SCD), recurrent pain crises, and the possible debilitating complications make patients prone to deficient self-care capabilities,

* Corresponding author. Building 255, Road 2904, Block 329, Salmaniya, Manama *E-mail address:* zrashwan@uob.edu.bh (Z.I. Rashwan). Peer review under responsibility of Chinese Nursing Association. psychological stress, depressive symptoms, and a poor quality of life.

- Empowerment-based interventions have become a widely used approach for patients with chronic illnesses.
- The current literature emphasized that the empowermentbased intervention represents a shift from focusing on facilitating deficits and addressing risks to developing personal power to perform activities of daily living.

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What is new?

- Empowerment-based interventions represent a shift from focusing on facilitating deficits and addressing risks to developing personal power to perform activities of daily living.
- The empowerment-based intervention grounded on the 5A model can be widely used to enable chronically ill patients to self-manage.
- This manuscript demonstrates that the empowerment-based intervention equipped patients with the necessary information and extended their awareness regarding the various measures that enhance their autonomy to perform self-care, encourage independence, alleviate pain, and prevent complications.

1. Introduction

Sickle cell disease (SCD) is an inherited autosomal recessive hemoglobinopathy in which there is a mutation in the beta polypeptide chain of the hemoglobin (Hb) [1]. This mutation leads to a decrease in the Hb oxygen-carrying capacity; hypoxemia will be evident. Several factors, such as dehydration, acidosis, infections, hypoxia, physical exertion, climate change, and altitude, may worsen the condition of SCD. Exposure to these factors may alter the shape of the red blood cells (RBCs), giving them a sickle appearance. Moreover, the aggregation of the sickled RBCs may occlude the small blood vessels, resulting in tissue ischemia. This vaso-occlusion (VOC), in turn, leads to various complications such as severe musculoskeletal pain, infections, heart disease, renal failure, stroke, leg ulcers, and proliferative retinopathy [2].

Globally, millions of people are affected by SCD, while individuals living in sub-Saharan Africa, southern and central America, Saudi Arabia, India, and Mediterranean countries like Turkey, Greece, and Italy are more likely to suffer from it [3]. In the Kingdom of Bahrain, SCD is a public health issue, and approximately 6,000 cases were registered in the electronic medical record system of the Primary Health Care Direction (2023) [4]. The disease is frequently associated with crises that may necessitate hospitalization and frequent visits to specialized clinics. Shaikh Jaber Alsabah Health Center had the highest number of visits (270 patients) [5]. Furthermore, the total number of admitted patients with SCD at the main governmental hospital was 4,694 patients in 2020, who required 35,114 days of care with an average length of stay of 7.5 days [6,7].

The Kingdom of Bahrain has prioritized sustainable development and the well-being of its population, particularly in terms of healthcare, emphasizing combating SCD [8]. Through a national plan and the implementation of numerous projects since 1984, including the establishment of specialized clinics and centers, advancements in blood transfusion services, and the introduction of telemedicine, the use of medications like Hydroxyurea and the introduction of Crizanlizumab have further enhanced treatment options for those patients. Despite these extensive efforts and advances in evidence-based SCD management, inadequate self-care capacity may hinder the achievement of the desired outcomes [9].

Self-care capacity refers to individuals' ability to perform activities of daily living (ADL) such as dressing, bathing, eating, shopping, and cooking. It also encompasses patients' involvement in their therapeutic activities to enhance their overall well-being, health outcomes, and quality of life [1,10]. Promoting self-care capacity is a priority nursing intervention, particularly for adults with SCD. From Orem's theoretical standpoint, "the ability to exercise self-care among individuals, families, and groups is an important consideration in the planning and delivery of nursing care" [11]. To accomplish ADL as well as manage pain effectively, patients with SCD should exhibit self-efficacy [12]. Self-efficacy is an internal belief in one's ability to control and manage disease symptoms daily to achieve the desired outcomes [13]. Several studies confirmed that the higher levels of self-efficacy helped these patients mitigate pain and manage crises and enhanced their ability to cope, stick to treatment plans, and effectively engage in self-care [9,13,15]. Nursing interventions are essential for managing patients' pain and applying preventative measures against subsequent sickle cell crises. Besides, nurses' responsibilities, particularly in the home and community setting, can be expanded or redirected to improve clients' overall self-management abilities [14]. Nurses can improve the self-care capacity of patients with SCD and foster their self-efficacy through continuous education and empowerment [15].

Empowerment is an enabling process through which individuals exert control over their lives by being equipped with the necessary information and extending their awareness regarding the available alternatives. This will allow them to make better use of their abilities rather than being passive recipients of professional care. Castro et al. claimed that patient empowerment is a more comprehensive concept than just patient participation and centeredness. Hence, this kind of intervention focuses on the individuals' strengths, capabilities, and adaptability [16]. Empowerment theory offers a unique conceptual framework for developing educational programs. It incorporates health promotion, symptom prevention, solving problems, boosting patients' self-esteem, and establishing trust [17,18]. It necessitates individuals to develop specific skills and positive assets, become motivated, and actively apply these skills and knowledge [19]. Thus, the empowerment theory concentrates on setting objectives and tactics for implementing change and optimizing the utilization of local resources and community services [20].

The 5A model operationalizes the empowerment theory principles and serves as a practical framework for the theory application by providing a clear step for guiding patients toward healthy behaviors [21]. Prochaska and DiClemente first proposed the 5A model regarding the self-change process toward smoking cessation [22]. In 2002, Whitlock and colleagues asserted that the 5A model offers a valuable evidence-based behavioral counseling intervention for clients with chronic illness in primary care settings [23,24]. It consists of five phases: assess, advise, agree, assist, and arrange [25]. By shifting the focus from provider-centered to patientcentered care, the 5A model empowers individuals to make informed health decisions, aligning with empowerment theory. For instance, the assessment phase seeks to deeply understand the client's unique circumstances, needs, and strengths, while the advice and agree phases facilitate a collaborative decision-making process where the nurse and patients jointly agree upon a plan of action that respects the client's autonomy and preferences [26]. The assist phase then supports the client's self-determination and problem-solving abilities, and the arrange phase ensures ongoing support and follow-up to sustain the client's progress and continued empowerment. Throughout the empowerment process, the nurse takes on a facilitative role, assisting the patients in implementing the plan and easing their access to the necessary resources rather than simply prescribing solutions [27]. This transformation, from the professional to the client as the expert in their own life, is a core tenet of the empowerment theory and is reflected throughout the 5A model's phases. When patients are empowered, they take an active role in their care, enhancing their sense of control and self-efficacy [21].

Empowerment-based interventions have become a widely used approach for patients with chronic illnesses. Utilizing empowerment-based intervention represents a shift from focusing on treating the disease and addressing risks to capacity development [28]. It emphasizes the client's active engagement, self-direction, and capacity to make informed choices, fostering a collaborative partnership that enhances the client's sense of control and confidence in making positive changes in their life [29]. Nurses can apply the 5A model to empower the self-care capacity among patients with chronic illnesses, including SCD, by addressing their unique needs through individualized consultations and tailored interventions [23]. Patients with SCD must take charge of their health by adopting self-care measures such as maintaining adequate oxygenation, hydration, a healthy diet, rest, and avoiding extreme temperatures. These measures help alleviate painful crises and reduce the need for healthcare intervention [30]. These strategies empowered patients to take control of their symptoms and fostered a belief in their ability to manage their health and enhance their self-care capabilities. In this context, a quasi-experimental study conducted by Ahmadi et al. examined the impact of selfmanagement interventions using the 5As model for empowering patients with SCD. They found that this model facilitated changing patients' health-related behaviors and promoted their self-efficacy [1].

There is a lack of research addressing the needs of patients with SCD in the Kingdom of Bahrain and exploring the effectiveness of different interventions in this susceptible population. By systematically assessing the patient's condition, providing tailored advice, fostering collaborative decision-making, offering necessary assistance, and ensuring appropriate arrangements for follow-up care, the empowerment-based intervention enables adults with SCD to control their disease process and have positive clinical outcomes [24]. This study investigated the effectiveness of empowermentbased intervention on self-efficacy and self-management capacity among adults with SCD.

2. Methods

2.1. Study design and participants

A single-blinded randomized control trial was carried out at two randomly selected health centers (HCs) in the Kingdom of Bahrain (ClinicalTrials.gov [https://clinicaltrials.gov/ct2/show/ NCT06296654] registration number: NCT06296654). This research article follows Consolidated Standards of Reporting Trials (CONSORT).

A cluster sampling technique was used to recruit the study setting and participants. According to health sector distribution, the Kingdom of Bahrain comprises four governorates. One governorate was chosen using a simple random sampling technique and a random number generator program (Northern governate). The Northern Governate includes seven Health Centers (HCs). Subsequently, two HCs were randomly selected: Shaikh Jaber Al-Ahmed Al-Subah and Budaiya HCs. Adult patients with SCD who fulfilled the following inclusion criteria: 1) receiving treatment from primary health care facilities, 2) being able to read and write, and 3) being willing to attend the educational sessions comprised by the study subjects. However, the exclusion criteria included patients who have a history of mental illness and advanced complications of SCD, such as multi-system organ damage and Opioid-Related Cyclical Withdrawal Syndrome [31]. Using the results of Ahmadi et al., the pooled Standard Deviation of the outcome measure was 5.62, and the effect size was 11.9 [1]. Using the following parameters: test power of 80% and 95% confidence level. Accordingly, the desired sample size was 64 for both experimental and control groups (32 each). However, considering a probable dropout rate of approximately 20%, the sample size was adjusted accordingly, and 38 participants were recruited in each group [32]. During the research period (starting in February and ending in May 2022), the

researchers assessed 149 patients for eligibility. After withdrawals at various points in the study, the final number of participants was 68 (Appendix A).

2.2. Randomization and masking

To get the sample, the electronic medical records of all adult patients with SCD were accessed, and a list of the eligible patients who fulfilled the inclusion criteria (sampling frame) was obtained. Then, they were invited to participate, provided basic information about the study, and introduced its aim and objectives. The block randomization method with a block size of 4 was used where one participant was assigned to the intervention group, and the next one was assigned to the control group 1:1 ratio [32]. The randomization sequences were created by a professional statistician who was not involved in the research processes. To ensure fairness and objectivity, the randomization sequence of the participants in both groups was kept in a secure place in two separate sealed opaque envelopes. As for the allocation concealment, the envelopes were opened just before initiating the interventions. The researchers also kept the data assessor and statistical analysts blinded [33]. The data were collected by a volunteer nurse who helped the research team distribute the questionnaire blindly without knowing the participant allocation and the study hypothesis. The biostatistician who performed the data analysis was not informed about the groups' assignment as the groups were coded as group one and group two [33]. Additionally, the research supervisors (Z. I. Rashwan) closely monitored the entire process of randomization and masking to ensure its proper implementation.

2.3. Interventions

2.3.1. Program development and validity testing

To design the empowerment-based intervention, the researchers conducted a comprehensive literature review to identify the existing research, best practices, and educational strategies for educating patients with SCD. The researchers also conducted a focus group with patients to explore their educational needs, preferences, and concerns regarding their condition. The participants' concerns revolved mainly around the following areas: a) basic information about SCD and b) self-management strategies such as hydration, dietary regimen and supplements, sports and exercise, minimizing infections, other instructions, medication compliance, and non-pharmacological pain management (Table 1). Based on the extensive literature search and the focus groups, the researchers developed the educational objectives and prepared the health education package about the management of SCD after thoroughly reviewing related literature.

To check the content validity of the empowerment-based program, a panel of experts in (n = 5) was invited to review the content and educational materials; two of them had more than 20 years of experience in SCD management, two of them were expert nursing faculty in medical-surgical nursing and one of them was expert in the clinical nursing research. The experts carefully reviewed the developed educational materials and provided invaluable feedback. For example, one of the experts suggested adding some interventions to empower the patients to maintain hydration, e.g., smartphone applications and challenge bottles. Moreover, one expert recommended adding updated treatment strategies for SCD in Bahrain. They also ensured that the content was tailored to the Bahraini context. The researchers refined the program accordingly. Eventually, the researchers finalized the educational program, incorporating feedback from the expert review process. They ensured the educational materials were seamlessly integrated into the clinical trial protocol and procedures, aligning with the study's

Table 1

General discussion sessions' topics and content

| Session topics | Content | Teaching strategies |
|--|---|---|
| 1.Basic Information about SCD 2. Self-management str | Definition of SCD and pathophysiological changes, clinical manifestations, complications, warning signs, diagnostic measures, and therapeutic management. ategies to prevent SCD complications | Lecturing, group discussion, video-based learning |
| a. Hydration | Hydration tactics, e.g., smartphone applications, challenge bottles, competitive games, and others, stimulate higher water intake via reminders and make hydration more enjoyable and straightforward. | Group discussion, and case-based learning |
| b. Dietary regimen & supplements | The optimal nutritional regimen included consuming nutrient-dense foods such as spinach, blueberries, broccoli, asparagus, eggs, avocados, oats, and so on. The researcher also emphasized the importance of glutamine, L-arginine, adding folic acid to the diet, and vitamin D supplements. | Lecturing, group discussion, video-based, problem-based, and case-based learning |
| c. Sports and exercise | Walking, running and yoga, taking sufficient rest in between sessions and exercises, drinking sufficient water before, during, and after physical activity, and maintaining a stable body temperature. Stopping exercise in the case of cramps, discomfort, swelling, weakness, or shortness of breath should be avoided. | Group discussion, problem-based, and case- based learning |
| d. Minimize infections | Compulsory vaccines and infection control precautions, such as hand hygiene and appropriate food preparation or cooking, were explained. | Lecturing, group discussion, demonstration |
| e. Other instructions | Strategies to reduce disease complications such as avoiding stress, altitudes and extreme temperatures and stopping smoking. | Group discussion |
| f. Medication compliance | The researcher provided some strategies to enhance patients' compliance with the prescribed medication such as using over-the-counter ibuprofen and/or acetaminophen, morphine, hydroxyurea, Antibiotics, and L-Glutamine. | Group discussion, case-based learning |
| 3. Non-pharmacologica pain management | l Massaging the painful body part, consuming fluids, taking a warm shower, using a hot water bag, placing warm towels on the affected part, and resting. Cognitive and behavioral techniques, including relaxation, deep breathing, distraction techniques such as mental imagery, and repeating positive phrases, can help patients adapt to pain. Physiotherapy, acupuncture, and distraction through activities (reading, video games, and movies) | Group discussion, problem-based, and case- based learning |

Note: SCD = Sickle cell disease.

timeline and logistics.

A pilot study was carried out on twelve patients with SCD to test the applicability and relevancy of the educational content. The researchers gathered participant feedback and monitored the program's impact, utilizing the evaluation data to refine and enhance the educational program. This approach ensured the program remained relevant and effective for the target population.

Eventually, the researchers prepared different audiovisual materials such as PowerPoint presentations, posters, and brochures. The researcher booked the conference room at Shaikh Jaber Al-Ahmed Al-Subah HC to deliver the educational sessions for the study group, while the control group received the routine healthcare SCD clinic at Budaiya HC. The preparation and arrangement phase lasts for two months. The empowerment-based intervention was conducted by the principal investigator, who is an advanced practice nurse with a master's degree in adult health nursing and has more than ten years of experience in managing patients with SCD daily.

2.3.2. The intervention group

The empowerment-based intervention included a) small-group discussion sessions, b) individualized consultations using the 5A model, and c) follow-up sessions.

2.3.2.1. Group discussion sessions. In the group discussion sessions, the researcher divided participants of the empowerment-based group into subgroups (6 participants per each) and discussed the content (Table 1) over two sessions for each group, the duration of which was 45 min. During the group discussion, the researchers empowered the participants to focus on topics relevant to SCD management, such as pain crises, warning signs, and cases that needed a referral to the emergency department. The session's objectives included 1) describing basic information about SCD, 2) discussing the health complications caused by SCD, 3) explaining self-management strategies that prevent sickling and SCD complications, 4) fostering compliance with medication and therapeutic regimens, illustrating the methods for dealing with the pain crisis. The researcher utilized different teaching strategies such as

lecturing, group discussion, video-based, problem-based, and case-based learning.

2.3.2.2. Individualized consultations and follow-up sessions. The researchers conducted one-to-one individualized consultation sessions to assess the patient's unique needs and provide tailored instructions regarding self-management using the 5A model (assess, advise, agree, assist, and arrange).

- (1) Assess. Initially, the researcher conducted individualized interviews with patients to examine their unique health habits, attitudes, and disease knowledge by asking questions such as "Can you tell me about behavioral health risks?" and "What are your health educational needs other than those provided in the general discussion session?" The assessment results were interpreted as a reflection of the patient's situation and as motivators for behavioral change in the patient. Their motivations and suggestions for improving their lives were also explored. For example, one patient expressed his struggle with hydration and forgetting to drink water throughout the day. The need for better hydration management was emphasized, leading to a deeper understanding of the patient's health challenges.
- (2) Advice. At this stage, the researcher provided detailed, individualized behavior modification advice regarding the personal health risks associated with SCD and its poor management, the benefits of behavioral change, and the drawbacks of the lack of disease control. For example, the researchers provided detailed instructions for a patient with poor hydration as follows: to improve hydration for patients with SCD, the researchers agreed with a patient to drink at least 2 L of water daily, utilizing a marked water bottle to track your intake visually. They also agreed on some objectives to achieve this goal, including making a habit of refilling the water bottle several times a day and always hydrating before physical activities, monitoring urine color to assess hydration levels, incorporating water-rich foods like fruits and vegetables into their diet, limit caffeinated beverages,

and increase water intake during hot weather and consult your healthcare provider for personalized recommendations.

- (3) Agree. The patients and the researcher agreed upon the behavioral change and the activities required to achieve the goals. Then, personally meaningful and prioritized behavioral SMART goals (specific, measurable, achievable, relevant, and time-bound) were set [29]. For example, one of the objectives was to - drink at least 2 L of water daily to help reduce the risk of pain crises. To develop behavioral objectives, participants were instructed to keep diaries of situations that caused pain crises and to bring the diaries to the next session. This process clarified expectations and empowered the patient to take ownership of the health management strategy.
- (4) Assist. At the assistance stage, patients were empowered by being allowed to make informed choices, raise awareness of their own personal power, frame a positive outlook, and formulate proactive self-management patterns. Participants were given personalized advice to help them regain control of their health and strengthen their abilities [1,34]. The researcher enabled the patient to integrate critical selfmanagement skills (i.e., action planning, problem-solving, and relapse prevention) into daily life. Patients were invited to the individualized session in the meeting room of the health center. For example, some patients reported the problem of forgetting to drink water. So, the researchers advised them to consider using a smart bottle that syncs with a mobile app to monitor their daily water consumption and provide real-time feedback on their hydration levels. These smart bottles can send reminders and alerts to the phone to prompt the patient to drink water regularly throughout the day. Additionally, it was suggested that a checklist could be created to remind the patient of these steps whenever pain was felt.
- (5) Arrange (follow-up). The researcher established a follow-up schedule. Weekly communications with the patients were made through social networking sites to check on the patient's progress, develop continuous interaction, provide ongoing assistance and support, and adjust the self-management plan as needed [23]. Individualized requirements were fulfilled a week later, either in person or by phone. Each patient was reviewed after one month of the study intervention by checking adherence to the specified continuous connection. The researcher reviewed the diary during the subsequent meeting to assess the patient's adherence to the hydration goals and the effectiveness of the strategies implemented.

2.3.3. The control group

In the waiting area of the SDC clinics, two expert registered nurses who hold Bachelor of Nursing degrees divided the patients in the control group into subgroups (6 patients each) and provided routine health education. To ensure consistency and clarity in the information presented, the nurses utilized the standardized health educational materials of the health center. For instance, patients were educated about the risks associated with dehydration, extreme temperatures, and high altitudes, which can trigger VOCs. Additionally, the nurses provided clear guidelines on when to seek emergency care, emphasizing the importance of recognizing severe symptoms. The education also highlighted the significance of regular medical examinations and screenings, with specific examples of crucial tests for disease management. For example, patients were informed about routine blood tests to monitor hemoglobin levels and the importance of regular check-ups to assess and manage potential complications associated with sickle cell disease. The educational session lasted 30 min, and the participants were encouraged to ask questions and discuss their challenges and concerns.

2.4. Ethical statement

Approval for conducting the study was obtained from the Scientific Research and Publication Committee, College of Health and Sport Sciences (CHSS SRPC No: 25/2021-22 dt. December 12, 2021). Official approval for conducting the study was also obtained from the Ethical Research Committee of the Primary Healthcare responsible Authorities (February 10, 2022). Written informed consent was obtained from the participants after the aim and objectives of the study were explained. Participation in the study was entirely voluntary. The right to refuse, participate, or withdraw from the study was emphasized. Confidentiality of the obtained data was assured, and participants' anonymity was respected.

2.5. Measures

2.5.1. Sickle Cell Self-Efficacy Scale (SCSES)

This scale was designed by Edwards et al. to assess the selfappraisals of adult patients with sickle cell disease for their ability to engage in daily functional activities [35]. It comprises nine items rated on a five-point Likert scale ranging from "not at all sure" to "very sure." The total score ranged from 9 to 45, with higher scores indicating higher levels of self-efficacy. The SCSES is reliable and valid for assessing clients' self-efficacy for engaging successfully in day-to-day activities despite having SCD. Cronbach's α coefficient for the SCSES was 0.89 [36].

2.5.2. The Appraisal of Self-Care Agency Scale-Revised (ASA-R)

According to Orem's self-care theory, Kearney and Fleischer originally developed this scale to assess the health-related self-care capacity level [37,38]. The scale consists of 15 items, rated on a 5-point Likert scale ranging from "totally disagree" (1 point) to "totally agree" (5 points). The ASA-R is a reliable (composite reliability indices >0.7) and valid (average variance extracted > 0.5) instrument for measuring self-care agency in the Spanish elderly population. According to Damasio et al., the ASAS-R showed good fit and reliability with the following three-factor model: Factor 1: having the capacity for self-care (items 1, 2, 3, 5, 6, and 10). Factor 2: developing capacity for self-care (items 4, 11, 14, and 15). These four items were reverse-coded [39].

2.6. Data collection

After their routine physician visit, eligible patients with SCD were introduced to the study recruiter, who eloquently described the nature of the intervention and the purpose of the research. Emphasizing that participation was entirely voluntary and would not affect the quality of their care, the recruiter invited these patients to join the study, fostering an atmosphere of trust and open communication. To capture the participants' experiences, the data collector, blinded to the study hypothesis and participant allocation, distributed the questionnaires to the participants in the waiting area of the SCD clinics. The data collector read all the measurement scales verbatim to the participants and allowed them to rate their responses accordingly to ensure accurate responses and facilitate the completion of the questionnaires, with the entire process taking approximately 15 min. The data was collected at two-time points: pretest and posttest, providing a comprehensive evaluation of the empowerment-based interventions and their impact on the participants' self-efficacy and self-care capacity.

Initial assessment (pretest): For both study and control groups, the researcher initially collected the baseline data by assessing the patient's demographic characteristics, clinical data, self-efficacy, and self-management capacity. Program evaluation (posttest): After one month, patients in both the empowerment-based intervention and control groups were reassessed for self-efficacy and self-management capacity.

2.7. Statistical analysis

The Statistical Package for Social Sciences (SPSS) version 23 was utilized for data analysis. Descriptive statistics included numbers, percentages, median, and percentiles (25 and 75) to describe demographic characteristics, self-efficacy, and self-care capacity. The data was tested for normality using the Kolmogorov-Smirnov test. It was revealed that the data of study variables was not normally distributed. Chi-square and Fisher's exact tests were used to test the significance of differences between the study and control groups regarding their sociodemographic and clinical data. Further, between-group comparisons regarding self-efficacy and selfmanagement capacity were done using the Mann–Whitney test (*U*). However, the Wilcoxon Signed Ranks test (*Z*) was used to compare the scores within the groups before and after the intervention. All the statistical analyses were considered significant at a 2- sided P < 0.05.

3. Results

A nearly half of the patients in both the study and control groups were 30 to less than 40 years old (47.2% and 43.8%, respectively). Moreover, 75.0% of the adults with SCD in the study group and 87.5% of those in the control group were males. Regarding educational level, it is observed that more than half of patients in both groups held bachelor's degrees (58.3% and 56.2%, respectively). The same table illustrates that 80.6% and 78.1% of patients in the study and control groups, respectively, had a family member with SCD, and more than half of the patients in both groups received blood transfusions the preceding year (58.3% and 53.1%). The comparison of different socio-demographic characteristics and clinical data among patients with SCD in the two groups is presented in Appendix B.

Table 2 reveals an improvement in the total score of self-efficacy from 30.0 (21.8, 35.8) to 37.0 (35.0, 39.8) among patients with SCD who received the intervention (P < 0.001). There was an improvement in self-care capacity among patients who received the empowerment-based intervention, as their median score was 26.0 (24.0, 27.0) compared to 22.0 (17.0, 24.0) in the control group (P < 0.001). The same table highlights that applying the empowerment-based intervention helped develop the capacity for self-care in patients with SCD, as their scores improved from 15.5 (14.0, 17.0) to 21.0 (18.0, 22.0) after the intervention (P < 0.001). The intra-group comparison also illuminates an improvement in the total score of self-care capacity among patients in the study group (P < 0.001 for the study group and P = 0.783 for the control one) compared to the control group and highly significant differences between the groups were found at the post-test (P < 0.001).

4. Discussion

This randomized controlled trial investigated the effect of empowerment-based interventions on self-efficacy and self-care capacity among adults with SCD. The results of the present study showed a significant improvement in self-efficacy among patients who received the empowerment-based intervention compared to those who received routine healthcare. Such a program enriched the participants with various strategies that enhanced their belief in having control over their unpleasant symptoms, suffering, and discomforts [29]. These strategies include but are not limited to disease management, such as utilizing non-pharmacological interventions to control pain episodes, e.g., using liquids, hot showers, hot water bags, and massaging [40]. Besides, it may also be helpful to educate them about the cognitive and behavioral techniques to deal with the pain, including relaxation, deep breathing, distraction techniques, and mental imagery. The program also included instructions on the importance of medication compliance and blood transfusions. It is worth mentioning that the empowerment-based intervention is not only focused on the physical aspect but also promotes the participants' beliefs in their efficacy in many areas, like mastery experiences, social persuasion, and emotional well-being. Therefore, high self-efficacy has been linked with numerous benefits to daily life, such as a healthy lifestyle, improved patient performance, and self-management capabilities [41]. As a result, it was not surprising that the majority of patients in the study group reported being able to reduce SCD pain through methods other than taking extra medication, doing most of the day-to-day activities, and managing SCD symptoms. Hence, they enjoyed doing things and dealing with the frustration of having SCD.

Several studies documented the impact of empowerment interventions based on Orem's nursing theory on the health-related quality of life and self-efficacy among patients with chronic illnesses [29,42]. These studies are in harmony with the findings of a quasi-experimental study conducted by Ahmadi et al., who found that self-management interventions using the 5As model effectively change behaviors and promote self-efficacy in patients with SCD [1]. Further, similar findings were reported in a randomized controlled trial conducted by Al Nasiri et al. in Los Angeles, California, USA [43]. The study highlighted the impact of smartphone technology in delivering an innovative family-based educational intervention program for improving knowledge and self-efficacy in SCD symptom management. However, our findings are compatible with those of Borimnejad et al., who conducted a randomized controlled clinical trial to investigate the effect of a family-centered empowerment program [44]. They concluded that implementing such a program is feasible and can increase self-efficacy in patients with chronic blood disorders.

Undoubtedly, self-care is crucial for the successful management of a chronic disease or condition, particularly SCD [45]. Nurses could enable patients to meet their self-care needs and develop their self-care agency through health education, direct nursing actions, and supportive care. As for the impact of the empowerment-based intervention on the patient's self-care capacity, the current study revealed that the application of this intervention enabled adults with SCD to develop their capacity for self-care as their scores improved after the intervention compared to the control group with significant statistical differences. This could be justified by implementing the empowerment-based intervention, the acquisition or modification of lifestyle, and effective coping strategies, which can reduce symptoms, promote self-management behaviors, and maximize the health outcomes among the study participants [1]. During the general discussion session, the patients were enriched with self-management strategies to prevent SCD complications, such as hydration, dietary regimens and supplements, sports and exercise, minimizing infections, medication compliance, and non-pharmacological pain management. In their systematic review, Gyamfi et al. (2021) found many randomized controlled trials conducted in low- and middle-income countries for SCD management [46]. The authors concluded that evidence-based interventions are effective for SCD management. They recommended that medicinal therapies be implemented in

Table 2

Comparison between self-efficacy, and self-care capacity among patients with SCD within two groups.

| Variables | Pre-intervention | Post-intervention | Ζ | Р |
|------------------------------------|-------------------|-------------------|--------|---------|
| Scores of SCSES | | | | |
| Intervention group $(n = 36)$ | 30.0 (21.8, 35.8) | 37.0 (35.0, 39.8) | -4.615 | 0.001 |
| Control group $(n = 32)$ | 27.0 (24.3, 30.5) | 28.0 (25.2, 32.0) | -0.913 | 0.364 |
| U | -0.834 | -6.121 | | |
| Р | 0.726 | <0.001 | | |
| Having the capacity for self-care | | | | |
| Intervention group $(n = 36)$ | 20.0 (17.0, 22.0) | 26.0 (24.0, 27.0) | -4.990 | < 0.001 |
| Control group $(n = 32)$ | 20.0 (18.3, 23.8) | 22.0 (17.0, 24.0) | -0.108 | 0.914 |
| U | -1.130 | -5.882 | | |
| Р | 0.262 | <0.001 | | |
| Developing capacity for self-care | | | | |
| Intervention group $(n = 36)$ | 15.5 (14.0, 17.0) | 21.0 (18.0, 22.0) | -4.627 | < 0.001 |
| Control group $(n = 32)$ | 15.0 (13.0, 16.0) | 16.0 (13.3, 16.9) | -1.125 | 0.260 |
| U | -1.011 | -6.076 | | |
| Р | 0.315 | <0.001 | | |
| Lacking the capacity for self-care | | | | |
| Intervention group $(n = 36)$ | 11.0 (9.3, 13.0) | 15.5 (13.0, 18.0) | -4.584 | < 0.001 |
| Control group $(n = 32)$ | 11.0 (10.0, 13.0) | 12.0 (10.0, 13.8) | -0.956 | 0.339 |
| U | -0.754 | -6.659 | | |
| Р | 0.454 | <0.001 | | |
| Scores of ASA-R | | | | |
| Intervention group ($n = 36$) | 47.0 (40.3, 51.0) | 61.0 (58.3, 65.0) | -4.668 | < 0.001 |
| Control group $(n = 32)$ | 48.0 (41.0, 51.8) | 49.0 (43.3, 53.0) | -0.275 | 0.783 |
| U | -0.456 | 0.654 | | |
| Р | 6.372 | 0.003 | | |

Note: Data are Median (P₂₅, P₇₅). U: Mann-Whitney U test; Z: Wilcoxon Signed Rank. SCSES = Sickle Cell Self-Efficacy Scale. ASA-R = the Appraisal of the Self-Care Agency Scale-Revised. SCD = sickle cell disease.

conjunction with non-pharmacological measures to reduce SCD-related morbidity and mortality [46].

The developed self-care capacity can be linked to improved selfefficacy among the study group, which declared its ability to manage day-to-day activities. These results are congruent with Nagshabandi and Abdulmutalib, who found a positive correlation between self-efficacy and self-care management among patients with SCD [47]. The authors of this study recommended a multifaceted program to improve self-management, inhibit problems associated with SCD, and promote the disease-controlling process. In their secondary data analysis, Matthie et al. also found that patients with SCD may benefit from self-care interventions that maximize SCD self-efficacy and facilitate access to crucial information [12]. Along the same lines, an exploratory qualitative study was done by Tavares et al. at the hematology center of an inland municipality in Ceará, Brazil [48]. They found that educational actions aimed at guiding and supporting the patient with SCA enabled them to maintain self-care activities, reach proficiency, and successfully apply what Orem's self-care theory recommends. Besides, Amertil et al., who performed a study in a sickle cell clinic in Ghana, found comparable results. They confirmed that self-efficacy was shown to have a strong and positive correlation with selfmanagement [49]. Thus, the results may enhance self-care measures and reduce uncertainty about sickness, resulting in improved health outcomes

Since self-management instructions are a never-ending task for patients with SCD, the patients of the present study were followed up through social networking applications, e.g., WhatsApp, at both individual levels or through group interaction to monitor their selfcare practices continuously. Indeed, keeping in touch with the patients empowered them to apply the given instructions and minimize non-compliance [50]. A similar approach was adopted by Issom et al. in their mixed method study, which used chatbot messaging apps and virtually met patients to facilitate adoption and long-term engagement [2]. The quantitative findings of this study revealed that chatbots for health coaching were user-friendly, entertaining, and supportive of patients' autonomy. Qualitatively, participants were enthusiastic about using the innovative method and affirmed its use in SCD knowledge acquisition. Most participants in Issom et al. research proclaimed the system's practicality in educating them about recommended self-care practices for symptom avoidance [2].

Despite our sample's representativeness, this research did not include patients seeking treatment in secondary healthcare settings. The researchers also struggled with frequent withdrawals from the study at different stages. The study also has limitations related to the sample size, as conducting the study in a larger sample size may obtain more generalized findings.

5. Conclusion

Based on the results of this study, it is concluded that applying empowerment-based intervention grounded on the 5A model is effective in promoting self-efficacy and self-care capacity among adults with SCD. The study provides empirical evidence for the practicality of using empowerment-based intervention programs to deliver high-quality, effective educational interventions. Therefore, structured self-management programs based on the 5A model are recommended as a simple, straightforward, and cost-effective choice for nurses to empower patients with chronic illness.

CRediT authorship contribution statement

Zohour Ibrahim Rashwan: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing original draft, Writing - review & editing, Project administration. Hasan Abdali Khalil: Conceptualization, Methodology, Investigation, Writing - original draft, Data collection, Writing - review & editing. Leena Mohamed Khonji: Writing - original draft. Gayathripriya Narayanan: Writing - review & editing. Marwan Kamal Altheeb: Writing - review & editing. Roseben Pradeep: Writing review & editing. Rajeswari Krishnasamy: Writing - review & editing. Magda Mohamed Bayoumi: Writing - review & editing.

Data availability statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declaration of competing interest

The authors have declared no conflict of interest.

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Appendices. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijnss.2024.12.011.

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