



The Self-Management of Pain in Patients with Sickle Cell Anemia: A Qualitative Study

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ABSTRACT

Background: The management of sickle cell involves a strong emphasis on self-care throughout life. In this disease, the patient's ability to perform behaviors that help relieve the experience of pain enables the long-term adaptation of the patient to pain. **Objective:** The present study was conducted to describe the self-management of pain in Iranian patients with sickle cell anemia. **Materials and Methods:** The present qualitative content analysis was conducted on 19 purposively-selected participants. Data were collected through unstructured interviews and analyzed using the steps proposed by Graneheim and Lundman (2004). **Results:** Five main themes emerged from the analysis of the data, including adherence to the medication regimen, adherence to a particular lifestyle, having social support, receiving training from the health personnel, and adaptation efforts. **Conclusion:** The patients considered the regular use of the prescribed medications and adherence to their particular lifestyle as a means for managing pain attacks. They also benefited from social support, the training provided by the health personnel, and relevant adaptive mechanisms.

Key Words: Disease Management, Pain, Sickle Cell Anemia, Content Analysis.

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INTRODUCTION

Sickle Cell Anemia (SCA) is a chronic disorder that affects many of the body's systems and is identified by a disorder in the hemoglobin beta gene. This disease is one of the most common genetic disorders throughout the world. According to the latest statistics, there are 500 patients with sickle cell in southern Iran, particularly in Khuzestan [1].

In general, the management of sickle cell disease involves pain control, sufficient fluid intake, and the prevention of infections and other complications [2]. Pain is one of the main complications of sickle cell disease and the most common cause of hospitalization in these patients [3-5]. The management of such a chronic disease is primarily

carried out at home and involves a serious emphasis on self-care throughout life [6].

Self-care at home contributes to pain management and is therefore effective for the prevention of pain crises and emphasizes the importance of self-care for the promotion of health and living conditions [7]. Self-care management is essential for reducing health care costs and improving the health status and quality of life of SCA patients, and patients diagnosed with SCA need to learn how to manage their symptoms and gain control over the periods of their disease in order to have a higher quality of life [7].

Like other chronic diseases, SCA has many economic, social, physical, and psychological consequences for patients and their families, and pain attacks expose the

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patients to a risk of harm and even death. Proper treatment also requires the management of medications and treatment, the management of pain attacks, making lifestyle modifications and other issues. Nonetheless, no studies have yet been conducted to describe pain management in patients with SCA in the context of the Iranian culture, and very little information is available on how specifically these patients manage their periods of pain and what strategies they use to control their disease. Notably, the review of the literature revealed no written studies on these patients in Iran, and the majority of studies conducted in other countries on these patients were also quantitative and dealt with the attitudes of their caregivers toward the patients. In addition, given that nursing is a practical discipline with care at its core, the methods of caring for these patients have to be specifically and accurately determined. The present qualitative study was therefore conducted to describe the self-management of pain in Iranian patients with SCA.

MATERIALS AND METHODS

The present qualitative study was conducted using the content analysis method. Qualitative content analysis is a method of analyzing written, spoken, and visual messages and, as a research technique, it is regarded as a systematic and purposive method for describing a phenomenon [8].

The study population of this study consisted of the patients with SCA, medical personnel, and the family caregivers of SCA patients. The participants included 19 caregivers (medical and home) and SCA patients who entered the study through purposive sampling. The interviews were held in a hospital setting with participants' agreement. The demographic data of the participants were collected. The participants had the following characteristics: having a proven diagnosis of SCA made by a physician; able to communicate; being a home caregiver with at least one year of experience in home-caregiving; being a professional care-provider with at least one year of experience in providing care; and willingness to take part in the study and share one's experiences.

After obtaining permission and a code of ethics from the Ethics Committee of Ahvaz Jundishapur University of Medical Sciences and receiving a letter of introduction, the researcher began sampling at Shahid Baghaei 2 Hospital in Ahvaz and obtained written consent from the selected participants. She then provided explanations about the study objectives and the confidentiality of the data and obtained participants' permission for recording the interviews. Once they declared their readiness to take part in the study, the interviews began with a central question. The participants were asked what strategies they used to manage their pain attacks at home and how they

cared for themselves to mitigate pain. More probing questions were then asked to increase the depth of the interviews, such as "What do you mean by that? Please elaborate/give an example". The interviews lasted between 30 and 90 minutes (60 min on average) depending on the participants' conditions. All the interviews were held by the main researcher and concurrently recorded and then transcribed verbatim and typed up. All the verbal communications of the participants during the interviews were recorded, and their non-verbal behaviors, such as eye contact and face movements, were noticed and recorded.

The collected data were analyzed using the stages proposed by Graneheim and Lundman (2004). The recorded interviews were typed up and transcribed verbatim immediately after each interview. The whole interview transcript was then reviewed several times to obtain a general understanding of its content. Next, the interview text was divided into meaning units, and a summary of these meaning units was extracted and encoded. Then, based on the similarities and differences obtained through comparisons, these units were divided into categories and subcategories, and the themes were finally extracted as statements reflecting the covert and overt content of the data. It should be noted that the data obtained from each interview provided a guide for the next interview.

The four criteria proposed by Lincoln and Guba [9] were used for the greater accuracy and rigor of the data. To ensure the credibility of the data, adequate time was allocated to data collection and maximum variation sampling (in terms of age, marital status, education, etc.), prolonged engagement with the data and member check were used. In addition, an external check and a peer check were used to ensure the reliability of the data. To ensure confirmability, the researchers tried not to involve their assumptions in the data collection and analysis. Finally, to ensure the transferability of the data, attempts were made to provide a rich description of the process of data collection, encoding, and analysis. This research was approved by the Research Council and Ethics Committee of Ahvaz Jundishapur University of Medical Sciences in Iran under the code of ethics IR.Ajums.REC.1396,897.

RESULTS

A total of 14 patients (eight women and six men), three home-caregivers (two mothers and one spouse), one physician (hematology/oncology fellow) and one nurse (bachelor's degree) participated in this study. The participants' mean age was 29.25 years. In terms of education, four had high school education or below, four had high school diplomas, one had an associate degree, three had bachelor's degrees and one was a

hematology/oncology fellow. Six of the participants were studying at the time of the study.

Five main themes emerged from the analysis of the data, including adherence to medication regimen (anti-sickling drugs and analgesics), adherence to a particular lifestyle (keeping the body warm and avoiding catching a cold, regular intake of liquids, sufficient rest, avoiding tension, thermotherapy, and massaging the limbs), having social support (a supportive family providing both physical and emotional support, supportive classmates, and a supportive school), receiving training from the health personnel and adaptation efforts (positive analogy, self-entertainment, fatalism, acceptance of the disease, and apathy), which are explained in the following section.

Theme 1: Adherence to medication regimen

1.1: Anti-sickling drugs

The participants had perfectly understood that the foremost strategy for the prevention and control of pain and complications is the regular use of drugs affecting the blood concentration and preventing the sickling of the red blood cells.

"I take some pills to control my disease. One of them is hydroxyurea, which I take regularly every day" (P4, patient).

"There is a pill called Arginine; it dilutes the blood and makes the blood flow easier. I take it because our problem is that our blood thickens and our veins become narrow and then the pain gets us" (P1, patient).

1.2: Analgesics

The patients tried to overcome their problems through the relative control of their pain attacks and thus reduce the need to visit medical centers.

"When in pain, I self-treat with a diclofenac suppository" (P4, Patient).

"I don't always go to the hospital every time I'm in pain. I try to control it at home myself by taking an analgesic or acetaminophen" (P6).

Theme 2: Adherence to a particular lifestyle

The participants had realized that taking medications alone is not sufficient for overcoming their disease-related problems but is necessary for somewhat preventing frequent attacks and thus reducing the likelihood of disease-induced complications and helping maintain their health by controlling triggers of pain attacks and following a particular lifestyle.

2.1: Keeping the body warm and avoiding catching a cold

The participants had found out that keeping their body warm and avoiding catching a cold would help control the disease.

"Catching a cold is poisonous for us, I have accounted for this in my life and I don't often catch a cold..." (P5, Patient).

"... I put on lots of thick clothes when I'm going out or to work, so as not to catch a cold" (P2, Patient).

2.2: Regular fluid intake

The participants discussed the importance of taking sufficient fluids:

"... we were told to take lots of fluids. I drink water a lot, and I always carry my bottle with me on the street, at school, at university ..." (P4, Patient).

"I take fluids excessively. Like, when I get up in the morning, I have 2-3 glasses of water before breakfast" (P9, Patient).

2.3: Sufficient rest

Taking sufficient rest and avoiding tension comprised another strategy used by the participants to prevent pain attacks.

"If I could take a rest so my body could recover and have a good sleep, our body recovers by itself, which helps abate our pain" (P12, Patient).

"... when I do the house chores, then take a little rest in between, I won't feel too bad. For instance, when I vacuum the house, I rest, then get back to it" (P7, Patient).

2.4: Avoiding tension

Regarding the importance of tension and stress control, the participants remarked:

"I say, if I could reduce my stress and mental concerns, I swear I would never fall." (P2, Patient).

About the control of pain attacks, one of the physicians said:

"Avoiding any kind of stress is one of the ways that is strongly recommended to the patients" (P8, Physician).

2.5: Thermotherapy

Thermotherapy was another strategy used by these patients:

"I do thermotherapy at home with a hot water bag. It works for me for as long as it is bearable ..." (P13, Patient).

"In such conditions, my mother always used hot water on me, and bathed us every ten minutes, and laid us down in a warm water bathtub." (P5, Patient).

2.6: Massaging the limbs

Massaging the limbs in pain was another strategy used by the patients and their caregivers:

"I just massage it, and it gets better by massaging" (P10, caregiver).

"I don't always go to the hospital when I'm in pain; instead, my mum starts massaging it" (P14, Patient).

Theme 3: Having social support

3.1: Supportive family

3.1.1: Physical support

The role of family support has been so strongly put forward in pain control that it appears that disease control would be very difficult without it.

"When pain overcame me since my older brother also had sickle cells, which was worse, my mother already knew what to do and treated us so well" (P1, Patient).

"Actually, when I wasn't still married, my mother was always there and attended to me. She gave me medicines and massaged my feet with oil and applied ointments whenever they were hurting." (P15, Patient).

3.1.2: Emotional support

Psychological and emotional support by the family was also discussed among the other types of support.

"My brother leaves some of his works to me when he is too busy, and he pays me for them. My family helps me a lot in financial matters" (P1, Patient).

"My family empathizes with me a lot Well, these words are very heart-warming." (P16, Patient).

3.2: Supportive classmates

Participants' classmates and peers were also discussed as another source of support, as they understood the patients and helped them receive emotional support and get relieved from psychological harms.

"...since they know I have this disease, they're very kind to me. They take care of me when I need something or help me a lot with my studies." (P17, patient).

"All the kids were good at school. They were kind to me. We were all fellow-citizens and knew each other. They never said anything to remind me of my illness" (P18, Patient).

3.3: Supportive school

The school officials had shown their support upon learning about the students' disease by not being strict with them regarding physical education classes.

"I informed my teachers in junior high school, and they were very cooperative. They helped me a lot in the exams and took simple exams from me" (P19, Patient).

"During school, our teachers were cooperative. For instance, the physical education teacher cooperated with me a lot and asked me to do research work instead or perhaps prepare a wall newspaper ..." (P12, Patient).

4: Training by the health personnel

The participants also took advantage of the training provided by the health personnel as a pain management guide.

"The nurses gave me some training and told me to exercise and take a walk for 20 minutes a day, drink a lot of water and liquids, and stress is too bad, which meant that the pain would quickly return if I got stressed" (P11, Patient).

About offering training to the participants, one of the specialists said:

"We initially provide the patients with training in the scope of what the patient has to do for his own health, and we teach them how to manage pain" (P8, Physician).

5: Adaptation efforts

Although the patients had many problems in life in relation to the nature of the disease, they pretended that they were not different from others and were even more capable. They, therefore, turned to strategies for coping with pain attacks.

5.1: Positive analogy

Some participants had adopted a strategy of positive analogy to patients in much worse conditions or with incurable diseases such as cancer.

"I used to sit and wonder why I was like this. Then, when I got hospitalized, I would realize that there were many people in worse situations than me and that I was better than many, so I would thank God" (P1, Patient).

"I keep telling him that this is just another illness. There are so many types. What would have happened if you were paralyzed? What would you say then?" (P7, Caregiver).

5.2: Self-entertainment

The effort to keep oneself busy and entertained was another strategy used by the patients during their pain attacks to distract them from the pain.

"When my mind is on something else and I'm with the guys or talking to others, it's unbelievable how all my pain goes away." (P1, Patient).

"Whenever in pain, I try to entertain myself to forget the pain. I use all the strategies I have been taught, but I mostly try to engage my mind in something other than pain...." (P6, Patient).

5.3: Fatalism

The participants believed that the invisible and mysterious hands of fate were at work and they had to inevitably follow the path of fate and had no other choice in the matter at all and therefore surrendered to their fate.

"I feel this is God's hand that has dealt me and I should accept it and be happy. It has happened, and I can't do anything about it. Neither sorrow nor complaint is any good ..." (P5, Patient).

"Still, thank God, this has been my share, my fate, and nothing can be done about it. No one can fight his destiny" (P6, Patient).

5.4: Acceptance of the disease

The participants remarked about reaching the acceptance stage of their disease:

"Sometimes I would get so sad and asked why I was like this. But when I think that it is all in God's hands and nothing can be done, then I get to accept it" (P9, Patient).

"I say, let it be, this too shall pass. I have accepted it. God is glorious. I have come to terms with it, both with the disease and with the pain ..." (P11, Patient).

5.5: Apathy

About the use of apathy as a weapon, one participant said: *"I used to be so sad about being ill at first, but no longer, not anymore. I'm indifferent now"* (P2, Patient).

DISCUSSION

The results obtained on the self-management of pain in patients with SCA showed that all the patients and their families emphasized preventive and health maintenance measures. Solomon (2008) argued that medicinal therapies for pain attacks in SCA include medications such as Acetaminophen, NSAIDs, and corticosteroids [10]. In the present study, the participants used NSAIDs to control their pain attacks, which agrees with the results of Solomon's study.

Another strategy used by the participants to control their pain attacks was the regular use of anti-sickling drugs such as hydroxyurea and arginine. In one of the major studies on this subject, the patients receiving hydroxyurea experienced fewer pain attacks during their SCA crises [11]. In a study conducted by Morris et al. (2013), the use of arginine was recommended as an appropriate intervention to improve painful periods of vascular obstruction in children with SCA [12], which concurs with the results of the present study.

Another strategy used in these patients was adherence to a particular lifestyle, which was also the case in the present study. In their study, Jenerette et al. argued that keeping the body warm and avoiding catching a cold comprised one of the most comprehensive preventive strategies [7] which concurs with the present findings. Also in studies conducted by Cordeiro et al. in Brazil, and Forrester et al. in Jamaica the participants with SCA used methods such as fluid-therapy and avoiding high temperatures and excessive activity [13, 14].

Other strategies used by the participants were sufficient resting and stress management. In other studies, Sibinga et al. [15], Jenerette et al. [16], and Clark et al. [17] argued that sufficient resting and stress management were the most popular techniques for preventing and controlling pain attacks in patients, which agrees with the present findings. Thermotherapy and limb massage were the other strategies used by the participants. In their study, While and Mullen [18] and Carpenter et al. [19] reported that the participants had used non-medicinal therapies such as thermotherapy and limb massage in conjunction with analgesics during their pain crises.

In the present study, having social support especially physical support and emotional support from family members contributed to the management of pain attacks

in the participants. In one qualitative study, Jenerette and Lauderdale explored the life stories of 12 adult patients with SCA and found that a supportive family that provided physical support was a key factor [20]. Also, in a study conducted by While and Mullen on social support, the participants revealed that they had received emotional support from their parents [21], which agrees with the present findings.

Supportive classmates were also discussed in many studies as a source of support. In a study conducted by Forrester et al. [14] the participants considered a positive self-concept and social support as key factors that had helped them cope with their disease, and one of the items was support, received from peers and classmates, which had made them feel accepted by others.

The school officials' support for the participants with respect to their physical challenges and limited ability to exercise was heartwarming and a source of emotional and psychological support for them. In the study by While and Mullen [21], the participants with SCA stated that they had connected well with their teachers and had received appropriate psychological support with regard to their conditions and limitations, which concurs with the present findings.

Another finding of the study was the counseling and training the patients, received from the health personnel that had improved their conditions and facilitated living with SCA or caregiving to its patients. Similarly, in the study by Jenerette et al., the participants noted the importance of personnel's knowledgeable care and following their advice [16].

In the present study, coping strategies such as positive analogy and comparing oneself with people with worse conditions and self-entertainment were common among the patients as adaptation approaches. Quoting Scolter, Rahzani, et al. argued that in Festinger's Social Comparison Theory, people constantly compare themselves with others, and comparing oneself with someone with worse conditions improves one's own mood [22]. In addition, Jenerette et al. [7] reported that patients used mental distraction strategies such as watching TV and surfing the web to comfort themselves, which agrees with the present findings.

Another coping strategy used by some patients that enabled them to live with their disease and bear it was the resort to religious beliefs and the acceptance that the disease is a God-sent and that they have no choice but to accept it. The present study concurs with a study conducted by Hasan Khani, et al. [23] although this point has been less highlighted in studies conducted on chronic diseases in other countries, especially in non-Asian countries, it has proven very prominent in Iran with its Muslim majority population and religious culture, where

religious beliefs are naturally expected to be used as a coping strategy.

In the present study, acceptance of the disease and trying to put it out of one's mind and thoughts as coping strategies were other approaches for maintaining one's psychological adaptation. Gonascent et al. found that acceptance was the most common strategy used by an adult with SCA [10], and Chandran [24] found that patients with epilepsy tend to belittle their disease and pretend to be normal, which agrees with the results of the aforementioned study. It is worth noting that the present study was conducted on an Iranian population and the results should only be generalized to other contexts and cultures with caution.

CONCLUSION

The present findings show that following one's medication regimen and a particular lifestyle are not enough for patients with Sickle Cell Anemia (SCA) to cope with pain and live a quality life, and it is also essential for them to use any social support they receive, the training and information given to them by health personnel and positive coping mechanisms. In addition to teaching these patients how to achieve self-care, nurses and nursing students should also be familiarized with pain management strategies for patients with SCA.

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