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# Lived Experience of Sickle Cell Patients during and after Crisis

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## Abstract

**Aims and Objectives:** To understand the lived experience and needs of patients with sickle cell disease during and two weeks after their crisis and identify the obstacles faced by patients while they are in the hospital. **Background:** Although there is no specific data of a number of affected individuals with sickle cell disease in Oman based on their age, the majority of the Omani population are youth. This category of the population is either in their high school or working in the governmental or private sector in the country. When the most productive category of the population are getting frequently absent due to sickle cell crisis and complication of sickle cell crisis from their work, this leads to huge financial and human resource burden. **Design:** Phenomenology. **Method:** This qualitative descriptive research was conducted using face-to-face interviews based on an interview protocol. The interview protocol was developed by the authors based on a framework called domains of well-being. Twenty adult patients have been recruited for the interview after meeting inclusion criteria and were asked about their well-being and lived experience during sickle cell crisis. Authors used SRQR checklist in reporting the study. **Results:** Thirteen themes were identified related to patients' lived experience and their well-being during sickle cell crisis. Patients reported physical, emotional, social, and spiritual alteration. Major themes that emerged are communication, medical team interpretation of genuine pain, Emotional disturbance during the crisis, What does this study contribute to the wider global clinical community? Nurses and doctors should use therapeutic communication when dealing with sickle cell patients. Nurses should establish rapport and trust with patients. In each health care setting, there should be a social worker to deal with patients with chronic illness social relationships

between the patient, family and friends, post-discharge status, spiritual and Islamic activities, and physical abilities. **Conclusion:** Participants' physical and psychological statuses were mostly affected. Moreover, participants experienced extreme emotional disturbance during a painful crisis. However, it was not well understood why participants experienced post sickle cell crisis symptoms which need to be further investigated. **Relevance to Clinical Practice:** Understanding the lived experience of sickle cell patients may help improve nursing and medical care provided to them and enhance better outcomes for patients. These findings made the nurses and physicians plan a strategy of treating sickle cell patients using a holistic approach.

## Keywords

Sickle Cell Patients, Lived Experience, Phenomenology, Face to Face Interview, Well-Being of Patients

## Main Outlines

- Adult affected with sickle cell disease were interviewed to elicit their lived experience.
- Interview protocol was structured based on well-being domains that are physical, social, psychological, and spiritual status.
- Thirteen themes were identified related to patients' lived experience and their well-being during sickle cell crisis.
- Major themes that emerged are communication, medical team interpretation of genuine pain, Emotional disturbance during the crisis.
- The wellbeing domain is largely affected because of chronic illness and mainly at the hospital. Physical, social, psychological and spiritual wellbeing are not intact during painful crisis.
- Novelty of the study: A. This study highlights the need of a holistic approach for patients with chronic illness as they may encounter major disturbance in their well-being status. B. This study explored the post-discharge symptoms that are not reported in the literatures. These symptoms are not related to the initial painful crisis and need further exploration of the cause and correlation with patients' characteristics.

## 1. Introduction

Our health status is affected by many factors, some are inherited, and others are acquired from the surrounding environment. Genetic disorders are very common and affect individuals all over the world. One of those is sickle cell disease (SCD). SCD is an autosomal, recessively-inherited, multi-faceted, chronic blood disease uniquely accompanied by vacillating, chronic, and acute pain attacks that require frequent interventions [1]. SCD affects millions of people throughout the world and is particularly common among those whose ancestors came from

sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy [1]. Oman is one of the countries that have a young population with SCD.

## 2. Background

SCD is considered the most common hereditary disorder affecting people all over the world which contributes to increase the mortality and morbidity rate in the prevalence area [2]. According to the recent World Health Statistics, around 5% of the children are carriers to SCD and around 300,000 children are born with this disease every year all over the world [3]. In Oman, about 2.7 per cent out of 1000 live birth are homozygous sickle cell disease which represents 81,000 people out of 3,000,000 from the total population [4].

Many studies have been conducted to understand the quality of life the sickle cell patients' experience. A photovoice pilot was conducted with a sample of youth living with SCD which concluded that doing things they liked made them feel more "normal" and helped them to distract their mind from the disease. Similarly, a descriptive qualitative study conducted by [5] found that majority of the adolescents confirmed an optimistic self-concept and described that they are getting strong support from their family and friends which made them feel recognized. Moreover, they reported ability to engage in social activities such as parties but they feel difficulties in engaging with sports activities. Thus, In order to address the challenges of the disease, various coping strategies were utilized such as praying, watching television, and surfing the Internet [5]. In the other hand, [6] conducted a qualitative study to investigate the lived experiences of adults over 30 years old living with sickle cell and showed that Physical, psychological, and social functioning were adversely affected by SCD. However, they reported that they were engaging with their family and friends in order to reduce the episode of crisis which helped in improving their health status. This study aims to explore the lived experience of Oman sickle cell patients during their crisis and after the crisis by two weeks.

## 3. Methods and Materials

### 3.1. Study Design

Qualitative research has been approved as successful methods used to explore the patient lived experience of SCD patients with pain as it provides deep insights for better understanding [7]. A descriptive qualitative methodology using phenomenology design was applied to understand the lived experience of patients with sickle cell disease during and two weeks after the crisis. This design present comprehensive summary of a phenomena and researchers do not penetrate their data in any interpretive depth [7]. Moreover, this approach allowed the researcher to demonstrate the clarification of adult human experience with sickle cell disease to shape and create their own understanding of their lived ex-

perience [7]. For the author to accurately explore and understand the lived experience, face to face interviews were conducted to collect data. One to one in-depth interview is proven in phenomenology study as it allows the patient to explore sensitive experience related to their disease [8].

### 3.2. Researchers' Characteristics and Reflexivity

Authors who conducted this phenomenological study are all nurses with a minimum qualification of post basic Diploma and the main author had formal training on research and holds a MSC in advanced nursing. All authors have no direct contact or relationship previously with potential participants as any previous or current relationship could affect the pre-assumption of patients' experience or disclosure of information. Reflexivity was maintained by recording all transcripts and allowing only two researchers to conduct all the interviews for the sake of information transparency, continuity of the same process of conducting the interview and ensuring the data saturation.

### 3.3. Study Site

This research was conducted at one secondary hospital at medical unit (wards and outpatient clinic). In each of these settings, there was a specific private room used for the interview to ensure the privacy and confidentiality of participants' information.

### 3.4. Sampling

The samples of this study were twenty citizen patients who were affected by sickle cell disease.

1) The inclusion criteria were:

- Being a citizen
- Aged above 18 years
- Being admitted or presented during their routine visits to the institution

2) The exclusion criteria were:

- Being non-citizen
- Age below 18 years

Purposive sampling using maximum variation sampling strategy was used to select the patients in this study to ensure enrichments of data (male and female patients, admitted and discharge patients, employed and unemployed, married and single). When researchers reached the data saturation, data collection was ended. The data saturation was identified by reading the transcripts and findings repetition of information from participants. A common pattern has been identified among these patients despite the variety of sample.

### 3.5. Conceptual Framework

For the human being to live well and achieve life goals, domains of wellbeing must be well maintained. This research was based on domains of wellbeing as a

conceptual framework (Figure 1). All participants were asked about their domains of wellbeing whether it is maintained or not during illness. The interview protocol included questions concerned about each domain. Physical domain means how able is the patient to perform physical activities and what is the physical status during the crisis. Social domain means the relationship between patient and the community during illness, psychological domain means the emotional status and psychological status during illness, spiritual domain means the relationship between patient and his GOD, satisfaction being sick and spiritual practice during illness. And the environmental domain was incorporated in all domains as the participants needed to express about the environment they live in.

### 3.6. Instrument/Data Collection Tool

The data collection process was based on a semi-structured face to face interview with each participant using an interview protocol. This protocol had been developed by four researchers based on the conceptual framework of human well-being (Figure 1). The protocol then was reviewed by three health care providers to ensure its validity. Probes were used to make sure of the depth of the interview. Since all participants' first language was Arabic, the interview was in Arabic and then Double check of translation processed by the principal investigator. All interviews were recorded in dairies to ensure the accuracy of the data and for the sake of storage and analysis in the future.

Data collection started in July 2014 and completed the required sample in December 2014. Scientific rigor was maintained by frequent consultation and peer validation of the data collection and analysis. Investigator triangulation was used in data collection, coding and analysis to ensure there liability of data collected.

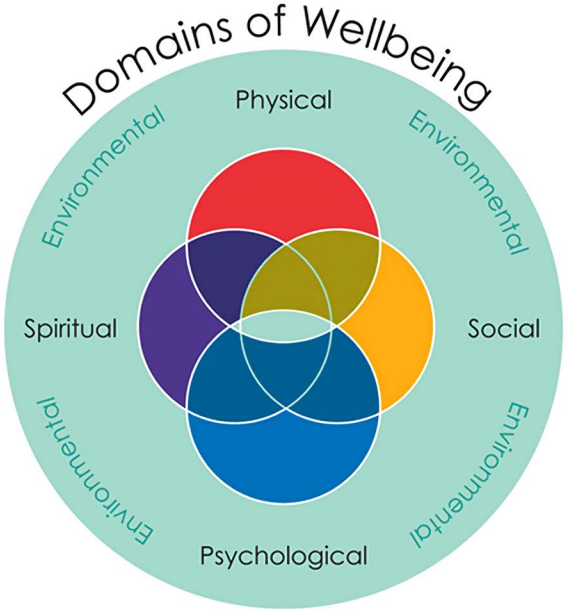


Figure 1. Conceptual framework.

### 3.7. Data Analysis

At the end of each interview, data obtained was reviewed by the researchers in the presence of participant to check the accuracy and a deeper understanding of the trends and justifications. Diekelmann's hermeneutical analysis approach was used to extract themes. This analytical approach is the hermeneutic circle and there is continual movement between the parts and the whole text being analyzed [7]. Diekelmann's hermeneutical analysis is seven stages process of data analysis that involves collaborative effort by a team of researchers. The process required all researchers to read interview texts for overall understanding. Then meanings were extracted for each interview and themes were identified. All themes were clarified by returning back to transcripts, drafts of themes and their definition with examples were presented to the research team, and then final drafts of themes were developed. During the analysis process, some themes were merged to prevent repetition and to strengthen the interpretation. Interpretations were considered in the context of the articulated theoretical framework. The triangulation method showed the corroboration of findings.

### 3.8. Trustworthiness of the Study

To ensure the rigor and increase the trustworthiness of the study, two types of triangulation was used. The first triangulation was investigator triangulation and analysis triangulation. In data collection, two researchers were conducting all the interviews. One of the authors was assigned to ask the open-ended questions and the second one is record keeping. This triangulation in data collection kept the data all the time with the same person until the end of all interviews. The second triangulation method used was in analysis and interpretation. Then the main author checked all transcripts translation, themes extraction, interpretation. This triangulation process allowed the authors to fully understand and avoid missing data by counter check of each author for other works.

### 3.9. Ethical Consideration

The study has been approved by the governorate research committee. The aim and objectives were reviewed and the questions of the interview were examined by the committee to accommodate the study objectives. After approval, all questions were explained to the interviewee and consent taken for their voluntary agreement. All participants were asked to sign informed consent once they agree to be involved. Participants' autonomy was maintained during the interview and the environment was checked for their safety. Participants were informed about their right to withdraw from the study at any time.

## 4. Results

Twenty participants from both gender (male and female) were involved in this study. Most of the participants had more than one crisis within one year. Thirteen of them were females. Among the twenty, six participants were married.

Nine participants were having a job and the remaining eleven had no job. Participants described how they felt; reacted to health care providers and community during pain and the major difficulties they encountered in their life due to disease and during pain. The findings are categorized into themes and sub-themes. Thirteen themes that were emerged along with their sub-themes and examples of quotes are listed in Table 1.

## 5. Discussion

Findings of this research revealed multiple breakdowns of human well-being cycle. These findings were supported by other researchers such as medical team interpretation of genuine pain [9], decreased physical abilities, altered social relationship and frustration [5]. Despite the management of pain during hospitalization, participants expressed symptoms after the acute painful episode that does not resemble the sickle cell crisis.

Table 1. Themes and sub-themes identified.

| Themes | Sub-themes | Quotes |
|---|---|---|
| **Communication** | 1) Nurses communication with patients<br>2) Therapeutic relationship | |
| **Medical team interpretation of genuine pain** | 1) Medical team response to patient<br>2) Addiction concern | "*In emergency department am hearing a lots of words, praying not to her it such as he came for morphine & his sister will follow him*" |
| **Emotional disturbance during crisis** | 1) Depression<br>2) Temper during pain<br>3) Emotional disturbance being sick | "*When am having the crisis, I feel I am different person not like other people and am continuously repeat why I am different than others*" |
| **Social relationship between patient, family and friends** | 1) Cultural impact<br>2) Community health | "*When am having sever pain, I want my family not my friends*"<br>"*I am feeling shy that my friends seeing me sick/having pain*" |
| **Accident and Emergency waiting time** | - | "*While entering accident and emergency, they are taking long time before starting treatment*" |
| **Hospital environment** | - | |
| **Restraints** | 1) Work limitation<br>2) School limitation<br>3) Social limitation | "*once I did interview to work in a company, and they reject me because of my sickness and I am depressed*" |
| **Post discharge status** | 1) Symptoms<br>2) Duration | "*after discharge, am still experience pain for several days, exhausted, sleepy and insomnia*"<br>"*Every time after discharge, I will not be able to sleep for two days*" |
| **Spiritual and Islamic activities** | - | "*I get disoriented with the time due of severe pain and I can't get out of the bed which affect my prayer*" |
| **Physical abilities** | - | "*I can't carry heavy items at home because am afraid that I will get backache and backache is the worst pain I experience it*" |
| **Pain** | - | *Am also getting back pain but lower and upper extremities is the most frequent pain which am experience it during crisis* |
| **Self-awareness** | 1) Crisis triggers<br>2) Pain management at home | "*am not taking medication because it is causing renal failure, doctors told me*" |
| **Others** | 1) Attitude<br>2) leaving hospital against medical advice | |

**Post-discharge symptoms:** Interestingly, Participants stated rebound pain after crisis attack and they believed it was part of narcotic side effects, these certain symptoms start after a painful crisis and they are different from sickle cell pain. These symptoms are; insomnia, strange pain that could not be described, vomiting, tingling sensation, lethargy, dizziness and disturbed vision, sweating and inability to walk. These symptoms last from two days to one week. However, there is no clear understanding of the cause of these symptoms and patients couldn't describe the pain that appears after discharge. This could explain anyway the reason for frequent emergency room visit after discharge.

**Emotional disturbance during the crisis:** During illness, participants experience extreme emotional disturbance that makes them a high temper and shouts sometimes. This temper could be due to morphine consumption as participants believe. This feeling could explain the reason for sickle cell patients' behavior in the hospital and their reaction toward healthcare workers. This finding is also supported by [10] that sickle cell patients do experience emotional disturbance such as self-hate, anxiety, and depression.

**Medical team interpretation of genuine pain and addiction concern:** Participants were disturbed when they were viewed as drug seekers and stated that their pain was not well understood by health care providers. Some nurses argue about pain level and they interpret the facial language to score pain and neglect the verbal statements of patients. These findings are in alignment with [11] and [9] that sickle cell patients were viewed as drug seekers.

**Social relationship between patient, family and friends and cultural impact:** Due to stigmatization, patients avoided contact with their friends and community during the crisis. Moreover, patients reported an inability to talk during severe pain and they avoid contacting with their family or friends during crisis. However, participants expressed that close family member such as mother, couple gives sense of comfort. Due to temper in severe pain, patients avoid talking with anyone and mentioned hesitance in communicating with health care workers. This is in align with literature that patients feel stigmatized and reported being anxious due to the cultural view toward sickle cell patients [12].

**Spiritual and Islamic practices** are affected during pain such as prayer time delay and inability to perform ablution due to pain or physical tiredness. Listening to the Holy Quran and reading RuqiyaShareeya (quotation from Holy book with some prayers) have an impact on pain level and comfort. However, it was not always possible for the patients to practice spiritual practice due to the hospital environment and the lack of specialist (spiritual guide) to assist them.

**Communication and leaving the hospital against medical advice:** Some patients tend to leave the hospital against medical advice due to lack of communication between patients and health care workers. Participants tend to avoid even hospital visit and try to manage their pain at home and this finding is in align with [11]. Moreover, nurses tend to misinterpret and underestimate patients' pain when reported.

**Hospital environment:** All participants reported discomfort in the hospital due to noise, and absence of preferred food. Participants suggested that hospital adopt certain menu to accommodate patients' preferences and manage noise level in the hospital. This may explain as well the emotional status of the patients and reaction during hospitalization as they do not feel comfortable.

**Pain:** Most participants described the pain as sever and suddenly starting. Mainly most painful parts were upper and lower limbs, chest and back pain. Majority of patients stated that pain starts suddenly at midnight or nap time. This character of pain differs from one patient to another. Therefore, healthcare workers need to identify each patient's pain character and plan individual patient care.

**Emergency Room waiting time:** Moreover, participants were kept waiting a long time in Emergency Room triage and their pain was not managed immediately. This finding supports the findings of [11] that waiting time in emergency Room is mostly 90 minutes before they receive their first analgesia.

**Physical abilities:** Regarding the physical abilities, sickle cell patients reported that they are less able to perform physical activities and they get easily tired. This finding is in alignment with [5] and [13]. Those patients who are having family commitments and responsibilities have a difficult time balancing between social life and taking care of themselves. These patients are more susceptible to a guilty feeling and usually require more family support to balance their social life.

**Restraints:** Participants experienced many restraints due to sickle cell crisis. Such of these restraints are socially related like the inability to join friends or family in picnics. Work-related limitations are the inability to find a suitable job, being rejected from jobs due to disease, and lack of cooperation of institution when reporting sick leave. School and college limitations are the inability to attend classes due to painful episodes, lack of support from college during a painful crisis and difficulty finding transportation from college accommodation to the hospital during a painful episode. Due to these obstacles and limitations, a number of patients do not have a job or left the college or school.

**Self-awareness:** Majority of participants are aware of their crisis trigger and they know how to manage in early stage. Participants expressed their knowledge on how to manage pain at home and what medication is more effective for them according to the pain scale. This finding supports the finding of [14].

Due to the limitation of qualitative research, the authors couldn't find the relationship between identified themes and demographics data of participants. Such as some patients who are involved in community work and having a job or married are less likely to visit the hospital or get admitted and those who are single and have no job are not more likely to visit the hospital. Moreover, patients who get frequently admitted they are more likely to have lack of communication and leave the hospital against medical advice. Therefore, nurses and medical team need to consider holistic approach and individualized care plan when dealing with a patient suffering from chronic illness. Such as, social life is affected due to frequent illness and hospitalization and this lead to emotional

disturbance. When the patient is emotionally disturbed, predisposing factors are most common in this stage and the patient suffers from the illness. Thereafter, when the patient is sick, his/her physical abilities are diminished and again this lead to reduced spiritual practice. Due to changes in spiritual practices, patient feels unsatisfied and get emotionally disturbed and the cycle continues.

## 6. Limitations

As this study is a qualitative one and used purposive sampling, the results cannot be generalized for the whole sickle cell disease population.

## 7. Conclusion

The findings of this study suggest that sickle cell disease patients suffer from disturbance in their life cycle. Most patients with sickle cell disease lack self-esteem and suffer from community stigma. During a painful crisis which is treated in the hospital, there are symptoms that remain untreated or neglected even after the painful crisis that is not well-understood. These symptoms do not resemble the painful crisis. However, these symptoms need further investigation in a larger population as the sample size is not representative of the whole sickle cell patients.

## Relevance for Clinical Practice

The current research suggests that a holistic approach of treatment should be developed. Other recommendations are involving a social worker in counseling the sickle cell patients in the community as well as developing a counseling team to follow such cases during the admission period. Future researches are recommended to identify the causes of post-discharge symptoms.

## Conflicts of Interest

The authors declare no conflicts of interest in reporting this study.

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