

CLINICAL RESEARCH

Pain self-management experiences in haemophilia patients: a qualitative study

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Background: Pain management can prevent long-term burdens in haemophilia patients and improve their quality of life. The present study aimed to describe and interpret pain experiences in haemophilia patients, focusing on pain self-management in their lives.

Methods: This was a qualitative study undertaken using a hermeneutic phenomenological approach. The study involved 14 haemophilia patients referred to a haemophilia clinic affiliated to Shiraz University of Medical Sciences in Iran. Data were collected using semi-structured interviews and field notes. Thematic analysis with van Manen's methodological framework was applied. Data analysis was performed using MAX.

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Researchers at Shiraz University of Medical Sciences, Iran, conducted a phenomenological study of patients at its haemophilia clinic to understand their lived experience of pain self-management

QDA qualitative software (2010). **Results:** Four themes emerged: a sense of self-awareness and recognition of pain and the factors that affect it, the ability to control and self-manage pain, gradually achieving self-efficacy in pain control, and using cognitive and spiritual strategies for pain relief. **Conclusions:** The study highlighted the essence of the lived experience of pain self-management and generated its linguistic description. By providing complementary therapy interventions, healthcare providers and family members could increase patients' self-awareness, recognition, ability to self-manage and control pain effectively, and competence in developing cognitive and spiritual strategies for pain relief.

Keywords: *Experience, Haemophilia, Pain, Self-management*

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Pain, as a common problem, leads to long-term burdens in haemophilia patients ^[1]. Pain management can prevent these burdens and improve various aspects of quality of life, including general health, physical functioning, mental health and social functioning ^[2,3].

At the time of writing, only a limited number of studies have been conducted focusing on pain management in haemophilia patients ^[4]. Approaches to treating pain in adults with haemophilia include both pharmacologic and non-pharmacologic modalities ^[5]. Pharmacological treatment is an essential part of managing chronic pain that needs to be modified according to the intensity of pain, ongoing response to treatment, and risk of adverse events ^[6]. Witkop et al. found that factor replacement was used for acute pain management in 79% and for persistent pain management in 38% of haemophilia patients ^[7]. Alongside the administration of factor, paracetamol was the only analgesic used in haemophilia treatment centres ^[4]. However, over-the-counter analgesics, such as ibuprofen and non-steroidal anti-inflammatory drugs (NSAIDs), are commonly used for pain relief by haemophilia patients. Additionally, non-pharmacological interventions, including physiotherapy, complementary treatments, and surgical (eg orthopaedic) or other invasive procedures, have been demonstrated as strategies for management of chronic pain in haemophilia patients ^[6,8].

For haemophilia patients, the most frequently used pain management strategies for acute and persistent pain consisted of the administration of factor, combined with some or all of the RICE method: rest, ice, elevation and compression ^[9]. In a study of 764 patients with haemophilia, the majority of the patients (84%) used factor concentrate followed by ice (78%), elevation (69%), and compression (65%) to treat acute pain ^[9]. In another study on children and adolescents with haemophilia, administration of factor, immobilisation and rest, ice and taking analgesics were reported as pain relief strategies ^[10].

Although a number of quantitative studies have been conducted on pain management in haemophilia patients ^[1,4,5,7,9,10], no specific evidence-based guidelines are available. Together, quantitative and qualitative studies can be used to inform evidence-based practice. Qualitative studies have been conducted on pain management experiences in chronic conditions such as cancer ^[11], HIV ^[12] and chronic lower back pain ^[13-15]. Some qualitative studies have also looked at the self-management of chronic conditions more generally,

including haemophilia, sickle cell anaemia, asthma, and diabetes ^[16-19]. Khair et al. carried out a qualitative study to understand self-management of haemophilia from the perspective of children with severe haemophilia, reporting that "boys develop self-management skills over time. They learn from healthcare professionals, their parents and other family members with haemophilia" ^[16].

Pain management and disease self-management have been demonstrated in a variety of medical conditions; however, there have been no qualitative studies that specifically focus on pain self-management in adult haemophilia patients. The present study aimed to describe and interpret pain experiences in haemophilia patients, with a particular focus on pain self-management.

METHODS

The study used a hermeneutic approach involving interpretive phenomenology. This aims to take an alternative viewpoint and to understand the patient's experience of pain by focusing on meaning and interpretation in their description of pain ^[20]. The study was conducted from March 2014 to April 2015. Study participants included 14 patients who attended a haemophilia clinic in Dastgheib Hospital in Shiraz, Iran, which is affiliated to the Shiraz University of Medical Sciences. All of the participants had either haemophilia A or haemophilia B (deficiency of factors VIII or IX), were aged between 18 and 75 years, spoke Persian, had pain experiences, and were alert and oriented. 'Pain experiences' in haemophilia patients were defined as having acute, chronic or ever-present pain in joints and muscles. Patients with cognitive impairment, untreated mental illness and other genetic diseases were excluded from the study.

The participants were selected through purposeful sampling, and semi-structured interviews and field notes were used to elicit their pain self-management experiences. When interviewed, the patients were first asked: "What are your pain management experiences in living with haemophilia?" and "What is the meaning of pain management in haemophilia patients' lives?" The interviews ranged from around 30 to 60 minutes in length, and were audio-taped and transcribed for data analysis.

MAX.QDA qualitative software (2010) was used for the data analysis. Data were analysed thematically, based on the phenomenological approach devised by Max van Manen. The patient's lived experience, and hence the essence and meaning of the pain self-management phenomenon, were identified through reading the transcripts using three approaches defined

by van Manen: holistic or sententious, selective or highlighting, and detailed or line-by-line readings of transcripts ^[21,22]. In the holistic reading, we looked for a critical phrase that might capture the fundamental meaning of the text as a whole. In the selective reading of the transcripts, the text was assessed several times to find what statement(s) or phrase(s) seemed particularly significant in pain management experiences. In the detailed approach, each individual sentence was examined according to what it revealed about the pain self-management phenomenon. This analysis continued until enough rich information was gathered and analysis no longer showed anything new or different ^[21].

The study was approved by the Ethics Committee of Shiraz University of Medical Sciences (EC-9371-7081; date: 9 July 2014), and informed consent for digital audio-taping of the interviews was obtained. The purpose of the study, the interviewing process, benefits and risks (such as anxiety or distress, confusion around the study process, and any potential physical, social or economic harm), confidentiality and anonymity were explained both verbally and in the participant consent forms.

In order to ensure the validity of the study, the researchers were careful to confirm that the phenomenological themes and insights that emerged were appropriate and original ^[21], and that the results reflected the participants' voices and the study's purpose. Purposeful sampling, prolonged engagement, participant checking of the researchers' interpretations and peer debriefing also formed part of the study methodology. Purposeful sampling was used to identify information-rich cases; the study participants were, therefore, haemophilia patients who were knowledgeable and experienced in pain self-management. The first author spent approximately two years in the haemophilia centre and was able to observe various aspects of its work, speak with the participants, and develop relationships and rapport with the healthcare team. The study participants were also asked to review the interpretive notes and thematic summaries once the data analysis was complete. Two expert phenomenologists assessed and approved all the study documents. In addition, the researchers ensured to provide sufficient descriptive data to enable its application to other contexts.

RESULTS

Four themes emerged from this study:

- A sense of self-awareness and recognition of pain and the factors that affect it;

- The ability to control and self-manage pain;
- Achieving self-efficacy in pain control gradually;
- Using cognitive and spiritual strategies for pain relief.

Self-awareness and recognition of pain and the factors that affect it

The study participants described a sense of self-awareness and recognition of pain, and used their awareness, knowledge, recognition and understanding to manage pain, and were also aware of the factors that had an impact on pain, reporting that pain was increased with physical activities, such as walking, jumping from height and exercising. In this respect, participant 11 maintained,

"When I played volleyball with friends with this painful leg, it was intensified."

In addition, psychological factors such as being lonely or being ridiculed by peers intensified the pain. In this respect, participant 1 stated,

"When a person is alone, the pain increases. Have you seen anyone who is in pain? They say they have more pain at night. When I'm alone, my bleeding and swelling cause more pain, bother more."

Control and self-management of pain

Study participants attempted to control and self-manage their pain using pain relief strategies



Self-awareness, recognition and understanding of pain and the factors that affect it are a key aspect of patients' ability to self-manage pain. Patients have reported recognising bleeds as a bubbly, tingling feeling inside the joint ^[16]

including administration of factor, rest and immobility, elevating limbs, taking analgesics, ice therapy, communicating with healthcare professionals and rehabilitation. Rehabilitation included physiotherapy, water therapy, occupational therapy, psychological treatments, and technical applications such as prostheses, orthoses and shoe adaptation.

Describing the quick recognition of pain and self-infusion of factor at the time of shoulder pain, participant 13 stated

"Last night at 4 a.m., I woke up, I felt I couldn't move my shoulder. I had pain. I noticed quickly. I got up and quickly prepared two factors and infused them to myself... Today I gave it a rest... I move my neck on this side [the painful side] less than the other."

He also used ice for pain relief:

"Now that I have pain, I put ice on it. It will numb the area in pain".

With regard to taking analgesics, elevating limbs and physiotherapy as strategies for pain management, participant 11 stated,

"I took painkillers to sleep. I took Novafen [an NSAID], paracetamol."

Participant 10 said,

"Most of the time, I take paracetamol and Gelofen [an NSAID]... I must lay a pillow under my legs... I came here for physiotherapy. Today is the second day. According to the doctor, I have to go to physiotherapy for 20 sessions."

In addition to having visited a psychologist as a result of being so anxious about his severe knee pain, participant 8 also referred to having hydrotherapy:

"I did a lot of water walking for my knee pain."

Participant 9 described taking medication for knee pain several times, insufficient treatment, and repeated visits to the haemophilia clinic:

"I took tramadol [the patient mentions the name of drug with embarrassment]. I had so much pain. I took it without prescription. I took

tramadol and prednisone. Again after three to four days, as I saw the pain didn't get better, I came here [the haemophilia clinic]. I've come to the hospital several times."

Study participants attempted to prevent the occurrence and intensification of pain by taking factor as soon as they could and self-managing their pain. They tried to adapt their lifestyle and modify and moderate their daily activities in order to better manage their pain. For example, participant 13 stated:

"I do my work more slowly and more cautiously. I don't do heavy work.... Sometimes, one should stop in life."

Describing how he managed his of daily activities on days when he had acute pain, he said:

"Now that I'm in pain, I adjust my work. I manage it more. If I do something every day, I see if I can do it or not. Today, I do easy and simple work, and I will do hard work, such as holding heavier objects, on the following days."

Gradually achieving self-efficacy in pain control

The study participants reported that they felt disabled at times of pain in their childhood, but that the negative effects of pain on their activities, thoughts and decision-making had gradually diminished. They were confident that the infusion of factor led to pain relief. Moreover, they felt that they were able to tolerate pain more compared to people without haemophilia.

Participant 7 stated:

"When I was in pain in childhood, I felt disabled... But as I got older, my attitudes and thoughts became different. I have pain in my hand [elbow]. I know the pain is there, I feel it, but I live with it. It doesn't bother me in a way that interrupts my mind... After experiencing it for many years, you know what the problems are, what happens. You know that if it's bleeding, with timely use of factor, it'll get better by 90% by the morning. If it doesn't get better, again, you use another dose after 12 hours – I am sure it will be a relief... So, with the pain that I have now, I do all [my] work and it doesn't affect my thoughts in a way that I can't make decisions."

Using cognitive and spiritual strategies for pain relief

The study participants used cognitive and spiritual strategies to manage their pain, including distraction, ignoring pain, diverting attention from pain, participating in social activities, communicating with members of their social network such as family and friends, avoidance, acceptance, communicating with God, and praying. Discussing distraction from pain, participant 3 stated:

"Even when I have bleeding and pain and I'm at home, I do a fun thing so that I forget the pain. ...The best thing is that I involve myself in my interests. I read my favourite subjects ... Or I do a simple task. It will help me forget the pain."

Moreover, participant 6 maintained:

"When a point on my body, like my ankle or anywhere else, is in pain, I repeat to myself that I will be calm soon. Then, I feel relaxed until the bleeding and pain will stop. This thought gives me the feeling that I'm calm."

With regard to communicating with God and praying, participant 3 stated:

"When I'm in pain, I always thank my God. As I can do my work, I again thank God. Always say thanks."

Participant 8 said:

"When I have pain, I'm closer to God, because in those problems humans can get close to God."

DISCUSSION

Based on the present study results, the experience of pain self-management means: a sense of self-awareness and recognition of pain and the factors that affect it; the ability to control and self-manage pain; gradually achieving self-efficacy in pain control; and using cognitive and spiritual strategies for pain relief. This broadly corresponds with the themes that emerged in Khair et al.'s qualitative study of self-management of haemophilia from a child's perspective, namely: "bleed recognition, self-infusion, self- and medicines management, pain and risk management, and conceptualising preventative therapy" [16]. It was also reported that haemophilia patients achieved wellness through individualised treatment, self-care, and an understanding of medicine management that diminishes bleeding frequency [16].

Study participants described their experience of pain management as a sense of awareness and recognition of pain and its affecting factors. Early recognition and intervention to decrease hypertrophy in epiphyseal growth plates in paediatric patients is necessary to reduce the long-term impacts of recurrent bleeding [11]. Although no studies have been conducted in this respect, it was reported that haemophilia patients recognised bleeding as a bubbly, tingling feeling inside the joint and performed treatment strategies as an essential part of haemophilia self-management [16]. Furthermore, a general sense of self-awareness was described as one of the strategies used by adult patients with sickle cell disease to manage their symptoms [17].

Study participants described self-management of pain as the ability to control and self-manage pain using pain relief strategies, including the administration of factor, rest and immobility, elevating limbs, taking medication, communicating with healthcare professionals, ice therapy, and rehabilitation such as physiotherapy, water therapy, occupational therapy, psychological treatments, and technical applications (eg prostheses, orthoses and shoe adaptation). Other studies have also reported rest, factor replacement, elevation, ice, compression, faith and prayer, and physical therapy as strategies used for management of pain in haemophilia patients [7]. Similar to this study, Heijen reports the use of rehabilitation such as physiotherapy, occupational therapy, psychology, social interventions, technical application and teaching



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The study found that cognitive and spiritual strategies were important aspects of the participant's pain self-management. These included communication with friends and family, participation in social activities and prayer

interventions by haemophilia patients with respect to managing pain ^[23]. Water walking (hydrotherapy) was one of the physical therapies used for pain relief by patients in this study. Therapeutic exercise and hydrotherapy have been shown to relieve the intensity of pain in haemophilia patients ^[24]. Overall, self-management is an essential part of living with a chronic disease ^[25].

In addition to factor replacement, study participants used over-the-counter NSAIDs (ibuprofen, Gelofen, Novafen), prednisone, paracetamol and tramadol for pain relief. Despite their doctors advising against their use, some patients reported using herbal medicines to manage their pain. NSAIDs and ointments for topical application (diclofenac and ibuprofen) were also used to alleviate pain. NSAIDs and paracetamol are the most common painkillers for both acute and persistent pain in patients with haemophilia ^[7]; ibuprofen and analgesics containing codeine and morphine are also used to relieve joint pain ^[26].

Similar to our findings, subjects of the study by Fisher et al. reported that they made lifestyle changes to accommodate their pain ^[27]. In our study, participants modified their work by focusing on more simple tasks, resting, and delaying more demanding tasks until their pain was under control. Adaptations to activity also included changing the way a task was carried out; for example, using assistive devices, requesting help from others and taking breaks ^[27]. Overall, haemophilia patients' daily lives need to be planned in such a way as to decrease the risk of bleeding ^[16].

In the current study, cognitive and spiritual strategies were also considered as a means to self-manage pain. This included distraction, ignoring pain, diverting attention from pain, participating in social activities, communicating with members of one's social network such as family and friends, avoidance, acceptance, communicating with God, and praying. Participants in the study of chronic pain by Ojala et al. described using various strategies to dissociate from their pain, "mostly thinking about something other than pain" ^[28]. Some subjects explained "how they forgot their pain when painting, laughing with friends or making love, which all were performed spontaneously with passion, enthusiasm and joy" ^[28]. Consistent with our study results, Merlin et al. reported that HIV patients defined self-management using cognitive strategies such as positive thinking ("being positive", "dealing", "ignoring", "fighting", "adjusting to", "learning to live with", "accepting", and "coping with" pain), relaxation and distraction. The subjects also described pain

self-management as spiritual strategies ^[12]. They also said prayers and focused on God for pain self-management. Participants in our study indicated that they avoided participating in some social activities in order to manage their pain. Similarly, Merlin et al., reported that HIV patients with chronic pain described avoidance of physical and social activities as a pain management strategy. Concerns about increasing pain and developing a mental image of pain being indicative of sickness/disease were the main factors affecting the decision to avoid or decrease physical and social activities ^[12].

One of the strategies for pain self-management reported by participants in the current study was communicating with members of their social network, such as family and friends. Ojala et al. stated that family members were the best supporters of those in chronic pain. According to their research, patients with chronic pain believed that they should not be left alone with pain; moreover, some of study participants stated that they could not live without the support of their peers ^[28].

Using a qualitative, hermeneutic approach was a strength of this study, in exploring the lived experience of pain management through findings based on the real-life experience of haemophilia patients. As with other qualitative studies, its limitation is that the data cannot be generalised to other patient populations.

CONCLUSIONS

The results of this study reveal that participants manage pain using various strategies. The core themes that have emerged could be used to inform the provision of pain management by healthcare professionals caring for haemophilia patients. Participants' awareness and recognition of pain and the factors that affect it, and their ability to manage pain effectively, is learned gradually through their lived experience. Given the gradual nature of learning to self-manage pain, it is important that healthcare providers intervene to help haemophilia patients achieve self-efficacy in pain management. This could include the development of educational programmes for healthcare professionals to be more aware of pain and how to treat it in the acute, chronic and acute-on-chronic phases that occur related to bleeding and arthropathy. These courses may include new imaging techniques, such as ultrasound for near patient testing of bleeding; the use of psychological therapies such as acupuncture; or cognitive and spiritual strategies, which were significant in self-managing pain for the participants in this study.

Healthcare providers should also be aware of the potentially positive effects of using such complementary and/or alternative approaches to pain management in haemophilia patients.

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