

ORIGINAL ARTICLE

Pain Experience in Hemophilia Patients: A Hermeneutic Phenomenological Study

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ABSTRACT

Background: Pain, as a crucial subsequence of joint hemorrhages in hemophilia patients, is chronic, debilitating, and distracting. This study aimed to describe and interpret pain experiences of hemophilia patients in their lives.

Methods: This qualitative study with hermeneutic phenomenological approach was conducted on fourteen hemophilia patients who had been referred to a hemophilia center affiliated to Shiraz University of Medical Sciences, Shiraz, Iran. The study question was “what is the meaning of pain in hemophilia patients’ lives? The data were collected through semi-structured interviews and field notes through purposeful sampling. Then, thematic analysis with van Manen’s six-step methodological framework was used. MAX.QDA qualitative software package, 2010, was used to analyze the data.

Results: The three main themes that emerged in this study were “alteration in physical health”, “engagement in psychological problems”, and “impairment in social relationships”. Alteration in physical health consisted of three subthemes, namely “impairment of physical function”, “change in body physics”, and “disturbance in sleep quality”. In addition, two subthemes including “nostalgia of pain in adults with hemophilia” and “psychological distress” emerged from engagement in psychological problems. Finally, “loss of social activity” and “change in relationships” were related to impairment in social relationships.

Conclusion: The present study highlighted alteration in physical health, engagement in psychological problems, and impairment in social relationship as a result of pain in hemophilia patients. Thus, healthcare providers and family members have to pay special attention to these problems. Besides, providing complementary therapy interventions is suggested for reducing these issues.

KEYWORDS: Experience; Hemophilia; Pain; Qualitative research

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INTRODUCTION

Hemophilia is a bleeding disorder that causes recurrent bleeding into joints, hemophilic arthropathy, and joint contracture.¹ One of the crucial consequences of joint hemorrhages in these patients is pain.² According to studies, 20% of children and adolescents with bleeding disorders treated in two European hemophilia centers in London and one Iranian hemophilia center in Shiraz were identified to have pain.³ Also, in a study on 6000 hemophilia patients, 35% of adults reported to suffer from 'chronic pain'.⁴

Pain imposes long-term burdens on patients with hemophilic arthropathy.⁵ It has also been recognized as a significant determinant of health-related quality of life in both children and adults suffering from hemophilia.^{4,6} Most pain in hemophilia patients is chronic, debilitating, and distracting.⁷ Thus, it may affect all the dimensions of hemophilia patients' lives. Pain was a crucial factor in hemophilia patients' functional limitations. Chronic pain also led to functional impairments and limitations.⁸ Garrido et al. reported that 89% of adults with hemophilia stated that pain interfered with their daily lives.⁹

Psychosocial distress may happen as a consequence of ongoing experience and burden of chronic pain.¹⁰ Chronic pain has been revealed to be associated with mood.^{8,11} Moreover, depression may also be seen in hemophilia patients because of suffering from long-term chronic conditions accompanied by pain.¹² Conversely, major depressive disorder has often been indicated to be associated with an increased incidence of pain complaints.^{13,14} Impairment in employment status¹¹ is yet another threat related to pain in hemophilia patients.

Up to now, few quantitative studies have been performed on pain in hemophilia patients; however, the findings of quantitative studies do not reveal the meaning or description of pain in patients' own words. Therefore, qualitative studies using phenomenological approach are necessary to describe the

patients' pain experiences. Some qualitative studies were conducted on pain in chronic diseases, such as diabetes,¹⁵ osteoarthritis,¹⁶ cancer,¹⁷⁻¹⁹ renal failure,²⁰ non-malignant musculoskeletal pain,²¹ low back pain,²² and osteoporotic pain.²³ According to the findings of these studies, patients in each of these chronic conditions had different experiences about pain in their lives. Nevertheless, review of the literature showed that a limited number of qualitative studies have been conducted on pain experiences among hemophilia patients.²⁴ For instance, a qualitative study indicated that adult hemophilia patients experienced acute intense pains explained as terrible, severe, intolerable, and unbelievable. In fact, as joints got damaged as time went by, patients experienced continuous and constant pain. They also coped with ever-present pain in the immobile joints, explained as intense, annoying, and intolerable. Due to the fact that this disease affects patients since birth and pain results from recurrent bleeding into the joints, hemophilic arthropathy, and joint contracture, the meaning of pain in hemophilia patients might be different from that in other acquired or later onset chronic diseases. Thus, this study aims to describe and interpret pain experiences in hemophilia patients in their lives. In order to describe and interpret pain experiences, we used interpretive phenomenology (hermeneutic) as the philosophy and method in this study. Phenomenological studies aim to provide some insight into the meaning of phenomena in individuals' lives.²⁵ In addition, hermeneutics refers to the art and philosophy of interpreting the meaning of the phenomena. Hermeneutic phenomenology, as a human science that studies individuals,²⁶ is a method of abstemious reflection on the fundamental structures of the lived experience of human existence.²⁵ Overall, interpretive phenomenological studies aim at entering another world and uncovering the practical wisdom, possibilities, and understandings found there. Hermeneutic inquiry, which uses lived experiences, focuses on meaning and

interpretation.²⁷ The rationale for selecting the hermeneutic phenomenological method was that it provides a sound approach for understanding and interpreting the lived experience of pain in hemophilia patients.

MATERIALS AND METHODS

This qualitative study with a hermeneutic phenomenological approach was conducted in a hemophilia center in Dastgheib hospital affiliated to Shiraz University of Medical Sciences, Shiraz, Iran between March 2014 and April 2015. The study was also approved by the Ethics Committee of Shiraz University of Medical Sciences (EC-9371-7081, date: 9 July 2014). Additionally, informed consent was obtained for digital audiotaping of the interviews. The participants were also informed about the purpose of the study, the interview process, confidentiality, and anonymity.

This study was conducted on fourteen hemophilia patients with deficiency of factors VIII and IX. The inclusion criteria of this study were being >18 years old, speaking Persian, having pain experiences, and being alert and oriented. The exclusion criteria of the study were having cognitive impairment, untreated mental illness, and other genetic diseases.

The data were collected through purposeful sampling, which is a non-probability sampling method where the researcher chooses the subjects based on one's personal judgment about the most informative individuals. The hemophilia patients' pain experiences were elicited through semi-structured in-depth interviews and field notes. The interviews were performed in the conference room in the hemophilia center by the first author of this article. They were conducted between 10:00 A.M. and 2:00 P.M. Focus on pain experience was important in the interviews. As the hemophilia patients were interviewed about their pain experiences, it was necessary to stay close to the experience as lived. The interviews began with "What are your pain experiences in living with hemophilia?" and "What is the meaning of pain in hemophilia

patients' lives?" The subjects were asked to think of a specific situation, person, or event. The participants' responses were audiotaped and transcribed for use in data analysis. The transcripts were imported to the MAX.QDA qualitative software package, 2010. Each subject participated in one session interview. Therefore, fourteen hemophilia patients were interviewed. The interviews lasted for approximately 30-60 min.

The data were analyzed using van Manen's (1990) six-step methodological framework.²⁶ In the first step, i.e. turning to a phenomenon, the phenomenon of interest that was the patients' pain experience was selected. The second step, investigating the lived experience of pain, was conducted through in-depth interviews with the hemophilia patients; it allowed us to listen to the pain experiences as expressed by them. Each subject in their description showed the nature of pain from their personal experience and these descriptions were recorded for later written transcription. The third activity was reflection on the essential themes that characterized pain. In order to achieve the meaning of pain experience, thematic analysis was used. Holistic, selective or highlighting, detailed, or line-by-line readings of the transcripts were applied for thematic exploration of descriptions of pain experiences.²⁵ In this step, after reflecting on each transcript once while listening to the audio recordings, the themes emerged from the pain experiences. From the themes, the essence of the pain was approached. The fourth step, describing pain through the art of writing and rewriting, permitted the investigator to shift from the internal to the external and to construct a clear description. In the fifth step, i.e. maintaining a strong and oriented relation with pain, the study question was focused strongly. The study question was always referred to when listening to the audiotapes, reviewing the transcripts, and reflecting upon the themes. Finally, in the sixth step, i.e. balancing the research context by considering parts and the whole, the researcher got involved in

searching for answer to the study question.²⁶ Reflection and interpretation of the transcripts by assessing the parts and the whole was to purely and fully describe pain as experienced by adults with hemophilia. In this study, based on the phenomenological question, sufficient experientially rich information that made figuration of powerful experiential examples and anecdotes possible was gathered. This helped us deal with life as it was lived.²⁵

In order to achieve validity in this study, based on van Manen's explanation, phenomenological interpretation of the underlying meaning structure of the descriptions was tried to be valid and the phenomenological themes and insights emerged from the descriptions to be appropriate and original. In order to have a rich, deep, oriented, and strong text, the hemophilia patients explained about their life stories and the data were set as they reflected the participants' sound and emerged the meaning of pain experience. As to reliability, van Manen reported that phenomenological study of the same phenomenon can be various in different studies.²⁵ Therefore, this study was similar to other phenomenological researches. Moreover, as other qualitative studies, four criteria, including credibility, dependability, confirmability, and transferability, were used for developing trustworthiness. For increasing the credibility, purposeful sampling, prolonged engagement, member check, and peer debriefing were undertaken. Member checking was done in an ongoing way as the data were being collected (e.g. through deliberate probing to confirm that the subjects' meanings were understood) and after the data were fully analyzed. Member checking was also carried out in writing. In doing so, the researchers asked the patients to review and comment on interpretive notes and thematic summaries. This was done through face-to-face discussions with the participants. In peer debriefing, the researchers gave written summaries of the data, the emerged themes, and interpretations of the data. Furthermore, an audit trial was used to improve dependability.

In order to evaluate dependability, the study documents, transcripts, reductions, analyses, field notes, anecdotes, study findings, and the final report were assessed and approved by two experts in the field of phenomenology. As to confirmability, the researchers were concerned about the fact that the data represented the information provided by the patients and that the interpretations of the data were not invented by the researchers. In order to achieve this criterion, the researchers attempted that the results would reflect the patients' voice and the conditions of inquiry rather than their own biases, motivations, or perspectives. Finally, to ensure transferability, the researchers tried to provide sufficient descriptive data so that consumers could evaluate applicability of the data to other contexts.

RESULTS

This study was conducted on fourteen hemophilia patients with a mean age of 28.42 (SD=5.65) years. The majority of the subjects were married (57.14%), had no children (50%), and had high school, diploma, and graduate degrees (64.28%). Moreover, 78.57% of them were employed (Table 1). One subject who previously was a worker was now unemployed. Besides, two patients who had high school diplomas were unemployed. Also, six patients (42.58%) stated that they were dropped out of school because of multiple bleeding, hospitalizations, long-term treatment, signs, symptoms, and complications of the disease, and chronic pain. Additionally, two participants said that they had to avoid studying in their favorite fields as a result of the disease. Others also maintained that they selected their work based on their disease.

The three main themes that emerged in this study were "alteration in physical health", "engagement in psychological problems", and "impairment in social relationships". The themes and subthemes of pain experiences in the hemophilia patients are presented in Table 2.

Table 1: Socio-demographic characteristics of the hemophilia subjects

Variables	n (%)
Age, mean (SD)	28.42 (5.65)
Gender	
Female	1(7.14)
Male	13(92.85)
Marital status	
Single	6(42.86)
Married	8(57.14)
Education level	
Primarily school	3(21.43)
Middle school	2(14.29)
High school and diploma	5(35.71)
Academic degrees	4(28.57)
Number of children	
0	4(50.0)
1	2(25.0)
2	2(25.0)
Employment	
Employed	11(78.57)
Unemployed	1(7.14)
University student	2(14.29)

Theme 1. Alteration in Physical Health

“Alteration in physical health” consisted of three subthemes as follows: “impairment of physical function”, “change in body physics”, and “disturbance in sleep quality”.

Regarding impairment of physical function, the patients stated that when they had pain, their life was disrupted. They could not walk, stand up, run, or climb mountains. They also reported that sitting down, getting up, and moving were very difficult for them during

pain. About pain during adolescence, one of the participants mentioned, “*When I had pain, I couldn’t go to school. Well, I couldn’t have that (normal) physical movement... My daily activities were disrupted*” (ID 8).

The patients reported that pain led to a change in their body physics. The subjects stated that their walking pattern altered, their limbs and body became deformed and thin as a result of mal- use, and pain was accompanied with bleeding. Moreover, they indicated that they had claudication during walking. One participant who had pain from childhood maintained, “*Always when I had pain, my leg was bent and I walked on the toes. When I have pain, I always do that. This decreases pressure on my leg...My legs have become thin*” (ID 9).

Disturbance in sleep quality was another major problem resulting from pain. Pain led to sleep disturbance, sleep latency, interrupted sleep, disturbance in sleep duration, waking up during the night, and using medications for sleeping. In other words, pain reduced the efficiency and quality of sleep. One of the participants talked about his sleep disturbance, “*This morning, at 4 A.M., I had a nightmare, I woke up and figured out that I couldn’t move my arm and shoulder. My shoulder had bleeding, I had pain*” (ID 13). One of the participants also mentioned, “*Some nights, I did not sleep because of pain. I took a pain killer. I slept at 9 P.M. and woke up at 12 P.M. ...I couldn’t sleep because of the intensity of pain*” (ID 11).

Table 2: The themes and subthemes of pain experience in the hemophilia patients

Themes	Subthemes
Alteration in physical health	1. “Impairment of physical function” 2. “Change in body physics” 3. “Disturbance in sleep quality”
Engagement in psychological problems	1. “Nostalgia of pain in adults with hemophilia” 2. “Psychological distress”
Impairment in social relationship	1. “Loss of social activity” 2. “Change in relationships”

Theme 2. Engagement in Psychological Problems

“Engagement in psychological problems” included two subthemes, i.e. “nostalgia of pain in adults with hemophilia” and “psychological distress”.

The nostalgia of pain in adults with hemophilia was due to the fact they remembered their childhood and ‘life with pain’, ‘prolonged pain’, ‘trouble’, ‘feeling bad about pain’, and ‘nights and days with pain’. For instance, one participant stated, “*I remember everything was difficult. I was always in hospital. I do not remember days that I was calm. What I remember is pain, night pain, and insomnia*” (ID 14).

Psychological distress, including anxiety, regret, frustration, sadness, sorrow, and suffering, was also experienced as a result of pain. With respect to anxiety, the patients reported that they became nervous for a long period of time while having pain. They felt regretful about the day of the event. Overall, they showed frustration with feeling of aversion to pain, hatred of life, despair, and request to end of life. They felt sad, as well. In this respect, one of the participants stated, “*During pain, I became nervous all during the night till morning*” (ID 7). Another participant also talked about frustration saying, “*My God, I wish you took my life and I did not have so much pain. I wish that my ankle was cut so that I was not in pain*” (ID 11).

One of the concerns of the patients and their families was fear from bleeding, addiction, and complications after taking painkillers (e.g. non-steroidal anti-inflammatory drugs, codeine, morphine, etc.). In this respect, one of the participants maintained, “*Every night, my mom says that as you have hemophilia, you should not take too many painkillers; it may dilute your blood. Since I have hemophilia, sometimes if I had so much pain, I preferred not to take them. My father emphasized that I should take fewer painkillers and take only one tablet a day if I wanted to. It might cause bleeding or other problems..... And you might get addicted*” (ID 2).

Theme 3. Impairment in Social Relationships

“Impairment in social relationships” consisted of two subthemes as follows: “loss of social activity” and “change in relationships”.

Restriction or inability to participate in social activities, withdrawal from public places, and social isolation were the changes that happened as a result of acute and persistent pain. One of the participants remembered the times he had pain and bleeding at school: “*When I had pain, I had to come home*” (ID 3). For the patients, social isolation meant staying at home, being alone, and presenting alone in social environments. In this regard, one participant said, “*Before this problem happens to me, I always went out with my friend. But I cannot go now.... Most of the time, I am alone*” (ID 11).

Considering change in relationships, the patients revealed that they had disclosure and secrecy in their relationships. They reported disclosure in workplace with caution as well as disclosure and secrecy in family relationships. Regarding disclosure in workplace with caution, the participants indicated that sometimes they explained their pain to some special co-workers to reduce their expectations at work. One of the participant stated, “*Sometimes, I say that I have pain. I believe I should tell the trustees, those who do not look at me with pity. They don't have many expectations from me then*” (ID 13).

Hiding pain from the family to take care of them was frequently reported in the patients' interviews. For instance, one participant mentioned, “*I was trying to tolerate pain until morning. I hid the pain from my family. Because if I wanted to tell them about my pain, I felt upset and they were more upset*” (ID 11).

On the other hand, the patients also disclosed that they received and perceived their families' support during pain. In this respect, one of the participants said, “*When my leg was painful and I couldn't walk, my wife did my works. She loves me more. She brings me food*” (ID 4).

DISCUSSION

Alteration in physical health, engagement in psychological problems, and impairment in social relationships as a result of pain experience visualized the complexity of pain. In line with the findings of the present study, a previous research demonstrated that “chronic pain is life changing”.²⁸ This implies that hemophilia patients’ pain affects the physical, social, and psychological aspects of their lives.

Hemophilia patients’ pain also led to alteration in physical health, impairment of physical function, and change in body physics. It was revealed that pain interfered with daily lives of more than three fourths of adults with hemophilia; half of these patients showed that pain interfered with their daily lives moderately to extremely.⁹ Pain may also serve as the reason for some of the functional impairments reported by arthropathic hemophilic patients.⁸ Pain, as a barrier to doing valued activities, affected the everyday life.²⁹ Moreover, pain intensity had a major impact on physical quality of life in adults with hemophilia.³⁰

According to our findings, another limitation related to pain was disturbance in sleep quality. Sleep disturbances have often been a complaint among the individuals living with chronic pain.³¹ Pain was associated with poor sleep quality, awakening, and shorter sleep time. Moreover, the risk of sleep disturbance after experiencing pain was significantly enhanced in comparison to being painless.³²

During painful episodes, the hemophilia patients were engaged in psychological problems. Psychosocial distress might be attributed to the ongoing experience and burden of chronic pain.¹⁰ In fact, it has been recognized that “chronic pain triggers emotional distress”.²⁸ In this study, the participants experienced psychological distress, such as anxiety, regret, frustration, sadness, sorrow, and suffering, as a result of pain. They demonstrated frustration with feeling of aversion to pain, hatred of life,

despair, and request to end of life. It has been reported that pain was related to mood and was experienced as a stressor.²⁹ Besides, Williams et al. disclosed that headache and back and shoulder pain were associated with mood disorders.¹¹ In a study on patients’ experiences of chronic non-malignant musculoskeletal pain, an explanation for suffering emerged as a key theme. In that study, the patients felt worthless, afraid, agitated, ashamed, and guilty because of pain.²¹ Furthermore, frequent pain in patients with severe hemophilia was associated with negative thoughts about pain (e.g. anger, fear, isolation-seeking behavior, and anticipating catastrophes).³³ In addition, it was reported that these patients’ negative thoughts about pain influenced their psychosocial quality of life.³⁰

One of the patients’ concerns was fear from bleeding, addiction, and complications after taking painkillers. Consistent with our study, one research indicated that hemophilia patients were concerned about dependence on the prescribed analgesics.³⁰ Pain is an inevitable issue in hemophilic patients’ lives. Thus, using analgesics and painkillers is often necessary in these patients. However, some painkillers, such as non-steroidal anti-inflammatory drugs (ibuprofen, novafen, naproxen, aspirin, mefenamic acid, etc.) put the patients at the risk of bleeding. Some others containing codeine and opioid also have serious long-term side effects, including drug dependence and addiction. Hence, these patients and their families worry about these complications during pain.

The results of our study indicated that pain in hemophilia patients led to impairment in social relationships. During acute and persistent pain, these patients were restricted or unable to participate in social activities. Some of them withdrew from public places and did not participate in social activities. They stayed at home and felt lonely. Similarly, another research indicated that pain in the feet of patients with rheumatoid arthritis restricted their social participation, such as walking or shopping with friends.²⁹

Moreover, patients with low back pain often revealed a negative self-perception in social interactions, with shame and frustration regarding difficulties in doing their daily living activities.²² One other research also revealed that avoiding activities because of fear from pain or injury enhanced debilitation and social isolation.³⁴ Moreover, hemophilia patients were reported to participate less in full-time work compared to the general male population, and a large number of employed patients reported limitations in doing their jobs due to their condition.³⁵

In our study, the patients reported that sometimes they explained their pain to special co-workers to reduce their expectations at work. In a study on children and young people with hemophilia, approximately half of the participants mentioned that no one outside their family knew they had hemophilia.³⁶ Accordingly, fear from others' misunderstanding, fear from dismissal from work, and unwillingness to disclose pain and disease in the workplace were the reasons they did not explain pain to all their colleagues. On the other hand, some patients explained that this reduced their colleagues' expectations during the pain day. Consistent with our study, the results of another research indicated that patients with low back pain often felt misunderstood and unsupported, partly as a result of the absence of visible signs of the condition.²²

Our study demonstrated that the patients valued family support during pain. They received and perceived their families' emotional and instrumental support during pain. One other study also revealed that these patients were satisfied with support from their partners, families, and friends.³⁷ It was reported that family and friends sometimes provided support and helped the patients with low back pain in management of pain.²² Family support is of great importance in Iranian culture. In fact, family provides different types of support for its members. It was reported that Iranian patients with end-stage renal disease perceived high social support.³⁸

Social support enables the individuals to cope with stress³⁹ and some problems, such as pain.

Our study also indicated that pain changed their relationships. In the same line, Fisher et al. stated that "chronic pain reveals the strength of relationships". They reported that pain changed the relationships with family members and friends, and family members provided emotional support.²⁸

This study was performed on adult hemophilia patients and in some parts of their lives replacement factor was not available; thus, there was a limitation in our access to treatment of bleeding using an advanced approach. Hence, future studies are suggested to be conducted on patients for whom there is access to replacement factor all through their lives.

As adult hemophilia patients experience alteration in physical health, engagement in psychological problems, and impairment in social relationships during pain, providing some pain relief and psychosocial interventions are suggested to eliminate these problems. Moreover, nurses are recommended to pay more attention to psychosocial aspects of life during care for these patients. Furthermore, since hemophilia patients explained their pain as change in relationships, teaching communication techniques is warranted during pain in order to prevent the patients' isolation. In the current study, impairment of physical function and change in the body physics were experienced by the hemophilia patients with pain. Therefore, participation in exercises that strengthen the muscles around the joints and doing physiotherapy for repairing these impairments are recommended. Moreover, further research is necessary to be conducted on the factors that reduce psychosocial and physical complications of pain and the effective interventions in pain relief in adults with hemophilia. Understanding these factors and interventions might lead to improvement of these patients' health and quality of life.

CONCLUSION

The findings of this study indicated that pain

was experienced as alteration in physical health, engagement in psychological problems, and impairment in social relationships in hemophilia patients' lives. Thus, healthcare providers and family members are recommended to pay attention to these problems experienced by hemophilia patients as a result of acute and persistent pain. Complementary therapy interventions are also suggested for reducing these problems and improving the quality of life in this group of patients.

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