From Pain to Suffering: The Narrative Ethnography of Pain Experience Among Kurdish People with Chronic Skeletal Pain in Iran

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Abstract

In this study, the aim was to explore how persons with chronic skeletal pain describe pain and suffering experiences along a storyline from their past life, during the illness, and the future perspective of the illness. The study was inspired by narrative ethnographical approaches to health and illness. The data derive from nine-month observations at four pain clinics in Bukan, Iran, followed by qualitative, narrative interviews with 20 Kurdish men and women who suffer from chronic skeletal pain. A narrative analysis was undertaken to understand the complexity of the stories about pain and suffering, and on this basis, a storyline was identified based on three sub-narratives: 1) beyond illness (past); 2) living in pain (now); 3) the shadow of death (future). The findings highlight the participants' different understandings and meanings of pain and suffering and the ways in which they link past, present and future. The pain, when sustained, becomes part of the patients' lives. It creates a kind of suffering that takes the sufferer beyond the pain in a way that affects the prospects of their future life. In this condition, the patient is only waiting for death.

Keywords: pain experience, chronic pain, suffering, narrative ethnography, medical anthropology.

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Introduction

Although pain is an interdisciplinary phenomenon being studied from a medical, biological, psychological, and even religious perspective, the field of pain still seems to be in the hands of biomedicine, focusing on the neurophysiological aspects of reducing pain to a signaling system (Leder, 1990). By separating pain from its' cultural and social context while putting emphasis on the mere medical approach and neglecting the interactions of disease and culture, this approach has treated patients as passive beings that have no authority against the medical discourse (James & Hockey, 2007; Kleinman, 1992a; Lawton, 2003; Medved & Brockmeier, 2008). Also, by dominating the health field, the biomedical approach has marginalized other sciences that study the non-medical dimensions of the disease. In such situations, the mission of the social sciences in general, and medical anthropology in particular by studying the social and cultural dimensions of pain and illness, is to seek understanding of the experience and perception of the body and how a person's perception affects the experience of the disease (Eisenberg, 1977).

According to Kleinman (Kleinman, 1988, 1992a), disease is regarded as a natural phenomenon and pathological condition which is diagnosed by a medical professional, while illness is conceptualized as a cultural construction. He describes illness as a human experience of symptoms and suffering. He addresses this issue in such a way that characterizes chronic pain as a permanent feature and indicator of disease in human experiences that is one of the important issues in the field of health that biomedicine has failed to address (Kleinman, 1992b). Chronic disease may cause a biographical disruption that leads to a fundamental reconsideration of the person's sense of self. Persons with chronic diseases strive during the illness trajectory to

reconstruct their life story and identity (Bury, 1982). Kleinman defines chronic pain as common meanings by which patients try to determine the position of the illness. Patients sometimes experience pain as an uninvited external factor and express it as a response to social, cultural, and psychological conditions (Kleinman, 1992b).

Some illnesses are particularly embedded with cultural meaning—which isn't directly derived from the nature of condition—that shapes how society responds to those afflicted and influences the experience of that illness (Conrad & Barker, 2010). Also, all illnesses are socially constructed at the experiential level based on how individuals come to understand and live with their illness and pain. Indeed, experience may be totally unrelated to the physical parameters of the intensity and duration of pain nociceptive stimulus. Also, the body in pain both produces culture and is affected by culture; it reflects and reproduces culture (Jackson, 2011).

The present study explores how Kurdish persons with chronic skeletal pain in Iran describe pain and suffering experiences. The field of the study, Bukan, is one of the Kurdish cities of Iran. The Kurdish cities are located in the west of Iran. In addition to living on the border, Kurdish people are in minority of ethnicity, language, and religion. Iran is a multi-ethnic country. Health studies show a relationship between ethnicity and illness/health (Benjamins et al., 2003; Bousso et al., 2011; Koenig et al., 2001; Sternbach & Tursky, 1965). Kurdish people speak in Kurdish, while the official language in Iran is Persian. Therefore, most of the daily affairs, such as media activity, education, legal and administrative affairs, etc., are done in the official language of the country. Issues related to this minority appear when people face problems due to lack of proficiency in the Persian language. Studies show that language barriers impact access to care and satisfaction of healthcare services (Al Shamsi et al., 2020; Schur & Albers, 1996; Yeo, 2004). In terms of religious beliefs, the official religion of Iran is Muslim-Shia, while the Kurds are Muslim-Sunni. Some researchers (Benjamins et al., 2003; Bousso et al., 2011; Koenig et al., 2001; Wolff & Langley, 1968) highlight that religious beliefs have a prominent role in the health-disease process.

In this regard, the individual perspective, the mental dimension, and subjective experience of pain was emphasized in the context of being an ethnic minority in Iran. The aim is to explore how persons living with chronic skeletal pain describe pain and suffering experiences along a storyline from their past life, during the illness, the future perspective of the illness, and how these views shape current health behaviors and treatment decisions of patients.

Methods

Design and Ethics

The study is based on a qualitative narrative approach and ethnographic methods for generating and analyzing data. Ethnographic research is exploratory in nature and emphasizes creating opportunities to follow phenomena as they move in different contexts (Atkinson, 1990). Ethnographic observation and interviews are suitable for describing chronic pain as a process and for elucidating complexity over time. Observation gives the researcher the opportunity to study what people do (action data), and not just what they say they do (discursive data) in interviews alone (Fangen, 2010). Use of ethnographic techniques in the pain studies provide better insights than other methods (Gooberman-Hill, 2015). Through observation, the researcher gains insight into forms of behavior, verbal and non-verbal communication, interaction between the

Table 1
Inclusion and Exclusion Criteria

	Inclusion criteria	Exclusion criteria
Age	≥48 years (Due to the onset of menopause in women and the occurrence of chronic skeletal diseases among this group in this region)	≤48 years
Gender	Men and women	
Ethnicity	Kurdish people	Non-Kurdish people
Health condition	Diagnosed with chronic pain illness more than six months (according to International Association for the Study of Pain [IASP] definition)	Diagnosed with non-skeletal chronic illness
Health capacity	Being able to participate in 60 minutes interview	Seriously reduced cognitive capacity
Consent	Being cognitively able to give informed consent	Refusal to give informed consent; ending the interview

Table 2
Demographic Details of Final Sample (Narrative Interviews)

Participant	Gender	Age	Education level	Profession	Living area	Disease	Age of onset
Kobra	F	66	Illiterate	Housewife	Urban	Knee arthritis	40
Masoomeh	F	73	Illiterate	Housewife	Urban	Hip osteoarthritis	68
Delnia	F	82	Illiterate	Housewife	Rural	Knee arthritis Knee arthritis Lumber disc	56
Layla	F	70	Illiterate	Housewife	Urban	Lumber disc Knee arthritis	40
Afsaneh	F	57	High school graduated	Tailor	Urban	Lumber disc	51
Roonak	F	59	Illiterate	Housewife	Urban	Knee arthritis Lumber disc	44
Zohreh	F	49	Illiterate	Housewife	Urban	Knee arthritis Lumber disc Rheumatism	34
Somayeh	F	70	Illiterate	Housewife	Urban	Knee arthritis	48
Shahin	F	65	Illiterate	Housewife	Urban	Lumber disc	63
Zahra	F	64	High school	Housewife	Urban	Knee arthritis Lumber disc	27
Mina	F	53	Illiterate	Housewife	Urban	Lumber disc	49
Arezoo	F	53	Illiterate	Housewife	Urban	Knee arthritis	50
Fatemeh	F	57	Reading skills	Housewife	Urban	Lumber disc	45
Ahmad	M	56	High school	Driver	Urban	Lumber disc	41
Mostafa	M	53	Writing & reading skills	Civil servant	Urban	Lumber disc	50
Aziz	M	61	Illiterate	Farmer	Rural	Lumber disc	56
Mahmoud	M	48	High school	Driver	Urban	Lumber disc	37
Saeed	M	54	High school graduated	Civil servant	Urban	Spinal cord injury	44
Saman	M	51	High school	Self-employed	Urban	Hip osteoarthritis	48
Ali	M	62	Illiterate	Mason	Urban	Lumber fracture	59

participants, and the exercise of skills. In addition, physical characteristics of space and place, and the participants' background and appearance are described (Atkinson, 1991).

Anthropologists consider narrative ethnography as an attempt to transfer contacts and the representative and reflective conflicts of field contacts. So, narrative ethnography captures the connections, experiences, relationships, and interactions of the field alongside cultural tensions and conflicts (accurately and without distortion), and the researcher's own perspective in the field. In contrast to the approach that used the term "narrative ethnography" to highlight researchers' narrative practices as they craft ethnographic accounts (with particular attention to the participation, perspective, voice of the researcher himself, and especially his emotional experience in relation to the experiences of the people studied), the second approach, taking into account the naturalistic, structuralist, and methodological motivations and concerns of ethnography, focuses on the everyday narrative activity that unfolds within circumstantially situated social interaction, with an acute awareness of the myriad layers of social context that condition narrative production. The term "narrative ethnography" is used to signal the combination of epistemological, methodological, procedural, and analytical sensibilities that must be brought to bear to understand narratives in social context (Gubrium & Holstein, 2008). With respect to Harrowing, this study considered the traditions, culture, history, interpersonal relations, power differentials, and other aspects of community living as factors that both influence and are influenced by the individual, an approach that has naturalistic and interpretive foundations (Harrowing et al., 2010a; Harrowing et al., 2010b).

The study was designed according to ethical principles for clinical research with special respect for the participants' autonomy and the non-harm principle. All participants were informed orally and in writing about the background and purpose of the study, the right to voluntary participation, the opportunity to withdraw at any time, the opportunity to request that any information be removed, maintaining anonymity, and that all audio recordings are deleted after the study concludes. Informed consent was obtained both in advance of the interview and repeated before each interview as the participants' situation and desire for participation could have changed along the way. Participants were also informed that confidentiality, which included identity and personal information, would be maintained throughout the study. For this reason, all names in the present paper are pseudonyms. Also, regarding participants who were illiterate or poorly educated, if necessary and upon the participant's request, all information was also provided to their families. It should be noted that, during the field study, human and moral principles, and avoiding discriminatory treatment were fully considered.

In the event of strong emotional reactions, the interview was considered interrupted and possibly resumed later. However, participants were asked whether they feel able to continue the conversation. Experienced researchers working with vulnerable populations (Sivell et al., 2019) have pointed out that researchers should not assume that patients do not want to continue the interview and therefore don't make decisions on their behalf. Participants may be in a vulnerable life situation, and it is necessary to adapt the interview intensity to this. In the interviews, the researcher was particularly sensitive to the opportunities for participants to express themselves. The researcher always let the consideration of the

participant take precedence over a research interest.

Recruitment and Participants

In order to conduct this research, all pain clinics were first identified. Then, while visiting them, centers that focused on chronic skeletal patients were selected. The objectives of the research and the working method were explained to them. It is worth noting that they were also given a guarantee that the research would not comment on and interfere in any of the center's current affairs. Also, the names of the clinics and their personnel were avoided, and they were assured that if it was necessary to mention names, pseudonyms would be used. After obtaining permission, the researcher was present in the clinics a few months before the start of the fieldwork in order to get acquainted with the staff, environment, and workspace. In this situation, events, actions, and physical characteristics were observed, recorded, and implemented. These, in turn, led to monitoring all the details of the observations and recording of field events (objective, mental, and emotional).

At the start of the fieldwork, the researcher was introduced to the members and patients by the head of the pain clinics as a temporary member and university researcher. After the researcher was gradually accepted as a member and researcher in the pain clinics, he took on the role of a participant observer. Then, the participants were chosen according to the inclusion and exclusion criteria to conduct the interview. During the nine-month period at the four pain clinics, different persons with various pain experiences were visited in the clinics, and 13 Kurdish women and seven men with chronic skeletal pain were recruited.

Observations and Interviews

In addition to interviewing and hearing the story of the participants, other tools such as observation, taking notes, and field documentations like medical records were used to explain and describe all aspects of the research topic. This allows the researcher to be immersed in the context and be able to provide an interpretation and analysis that is close to the social worlds under study because analyzing the structures and contents of narratives isn't sufficient in ethnographic research; it is necessary to consider reports with motivation and attention to tellers and the cultural context in which the narrative happened (Cortazzi, 2001).

Ethnographic work depends on the interactions between the people in the research field and the researcher. During the fieldwork in the pain clinics, observations, taking notes and field documents (contextual data and action data, recording audio files, and then implementation), communication, and physical gestures in both field study and during interviews was recorded in Kurdish by the researcher, a native who belongs to the context and culture of the studied society. At the end of the observation period, individual narrative interviews were carried out. Pain experiences were explored through individual in-depth interviews in Kurdish conducted by the researcher. Therefore, according to the exact schedule, fieldwork and interviews were started. The interview guide was organized according to a timeline, and the participants were invited to tell their own story of what their lives were like before they became ill, how things changed during their illness, and their view about the future of the illness. The participants could move forwards and backwards in time in ways that occurred naturally to them (Riessman, 2008). Finally, in order to compile and write the results of the research work, all items were translated into English by the researcher himself. It should be noted that there were no challenging issues during the translation process.

Data Analysis

In this study, multi-source data were analyzed using Miles and Huberman's flow model (Miles & Huberman, 1994) and thematic narrative analysis (Riessman, 2008). The analysis was carried out and accompanied by three concurrent flows of activity: data reduction (process of selecting, focusing, simplifying, abstracting, and transforming data that appear in writing up field notes or transcriptions), data display (an organized, compressed assembly of information), and conclusion drawing/verification (Miles & Huberman, 1994). To gain an overall understanding, field notes and transcripts were read and reviewed several times to identify themes and to acquire a general impression. To achieve a thick description, in addition to the interviews, all field observations were also used for data analysis by performing concurrent flows of activity. By repeating this cycle during the research period, the data were reviewed, and the findings became richer and thicker. So, the author of this article (researcher) focuses both on the how (i.e., the external organization of the narrative) and on the what (the internal organization) questions to find the themes to link the past, present, and future experiences of the participants (Gubrium & Holstein, 2009) and to find the structure of their stories. In an attempt to ensure trustworthiness and validity of the research findings, Morse's approach (Morse, 2015) as well as Whittemore's (Whittemore et al., 2001) view were used.

According to Morse, rigor as a concept is an important goal and the concern of external evaluators who ultimately determine the worth of qualitative research. Rigor, comprising both validity and reliability, is achieved primarily by researchers in the process of data collection and analysis (Morse, 2015). For reaching rigor in this study, prolonged engagement, thick description (being present in the field, continuously observing, overthinking, drowning in data, combining field notes, documents, and interview transcripts, and analyzing them all together), and researcher bias strategies was used. Whittemore introduces primary and secondary criteria for reaching validity in qualitative research. Primary criteria (credibility, authenticity, criticality, and integrity) are necessary to all qualitative inquiry; however, they are insufficient in and of themselves. Secondary criteria (explicitness, vividness, creativity, thoroughness, congruence, and sensitivity) provide further benchmarks of quality and are considered to be more flexible as applied to particular investigations (Whittemore et al., 2001). So, in addition to primary criteria, secondary criteria for reaching validity were used.

Findings

The data analysis revealed that the participants' experiences of chronic pain and suffering varied over time from before they became ill to the future of their lives. Profound processes of change in the participants' daily life were identified. The findings can be summed up by the phrase "from pain to suffering" and will be presented as three narratives structured chronologically: 1) beyond illness; 2) living in pain; and finally, 3) the shadow of death. Each narrative will now be examined in some detail.

Beyond Illness

Usually, the participants' narrative of chronic pain and illness are accompanied by a description of their past active living conditions. They introduced themselves as active and vigorous.

Here is Delnia's story of how she saw her life and herself. The pain and illness were visible on her face. She sometimes paused

and sighed while speaking. During the interview, she would sit down and stand up several times. She would either lean against the wall or use her cane to balance and continue speaking in this position. It was clear that she couldn't trust her replacement knees:

In the old days [when living in the village], we had a lot of works, we were a large family. We used to raise livestock, bake bread, make milk, cheese, buttermilk, etc. In the past, resting didn't make sense. Most of the time, we ate while working; it was fun and there was no sadness. We were generally looking to do things and please the people around us, and the other things didn't matter. Because in the past, people's living conditions were the same. (Delnia)

The first storyline is formed from the past lifestyle of participants along with social, cultural, and economic structures providing the basis of illness and pain. By telling the past, participants prepare the introduction of their pain and suffering process. Many participants consider hard working conditions, lack of facilities, and environmental and cultural conditions as the main causes of pain and chronic illness. Pain and illness show themselves in the narratives of the participants. In these descriptions, they link pain to suffering that is rooted in the past. The geographical conditions and the specific natural environment of Kurdistan provide the basis for the cultivation of strong, tireless, and warrior individuals. On the other hand, the existing culture in line with these conditions prohibits any weakness and incapacity and calls people who are excluded from the cycle of daily activity, for various reasons such as illness and pain, lazy and incompetent. This issue is evident in Zahra's narration. She was an intelligent woman. Even now, with her physical condition, she seemed more cheerful and agile than other patients the researcher has seen in these centers. The length of disease seemed to have made the pain easier for her:

Since I was 27 years old [about 37 years ago], I grew up with this pain, and I have come to terms with it. I think my life has had this pain since the beginning because I don't remember this pain has been subsided. Sometimes, when the pain lasted for a long time, I couldn't sleep [well] for a month. I got married and had children at a young age. I had five children at the age of 27. Well, in a few years, I gave birth to five children. Maybe this caused my pain. I think kneeling. I used to lean on my knees to do some everyday activities like kneading dough, washing clothes, etc. I wasn't careful, and this happened to me. (Zahra)

This is also evident in Aziz's statements, but it also expresses another factor. He attributes his illness to hard working, environmental conditions, and lack of awareness about his physical health. He said:

The reason of my pain is working. I have reaped from morning to night. I have carried big racks for building the mosque in village. I was young and the young don't care whether it can do or not, or what things is harmful for health. (Aziz)

However, a closer reading reveals, in addition to these cases, the lack of awareness and health literacy play an important role in the illness and pain process. Like the difficult living conditions, the social and cultural structures of society have created limitations for them. Most of the patients have a low literacy level, and the families didn't want to educate their children. The continuation and completion of this storyline can be seen in Mostafa's narration:

Our misfortune is that we don't consider ourselves sick until we are worn out. For example, I was in pain for two or three years, but I didn't care. I used to say that it is nothing until this happened. If I minded my

illness, I don't get in trouble. I think anyone in my age is like me, they don't go to the doctor until the problem becomes acute. I didn't see myself sick because I wasn't disabled or paralyzed. As long as we can eat and move, we don't consider ourselves sick. (Mostafa)

It is what Saeed clearly believes. The researcher had known him for a few months. He looked older than his years. It was difficult to arrange an interview with him. The researcher could rarely see him because his physical condition prevented him from attending the clinic as scheduled. He had difficulty walking and trying to keep himself upright. He explicitly said:

I don't have a disease. I lost my L4 lumbar vertebra. Now, I can't move. I accept this disability, but the pain has damaged me. If I don't have this pain, I think I have no difference with you. (Saeed)

Living in Pain

The second storyline begins by dealing with pain and illness; a pain that slowly changes all parts of the patient's life. Now, the illness is a part of their life. The process of diagnosing the pain is very time-consuming and complicated. Delnia doesn't have a pleasant experience across many visits to doctors. She has experienced being given different diagnoses, taking different drugs, surgery, etc. She is also upset and worried about doctors not providing her with enough information:

At first, they [doctors] said you have arthritis. Then, another doctor said that there is a problem with your back, and you need to undergo surgery. The doctor didn't give us much information about the illness and the treatment. For example, someone said that you have no choice and only have to take medicine. He prescribed very expensive medicine and it didn't have any effect. Another doctor said that I will surgery your knees, but the cost is very high. He said that I don't know what the result of the surgery will be. I had to surgery my back, but a few years later, my legs got worse. We were supposed to do a gel injection, but it didn't work, and then I had joint replacement surgery on both my knees. (Delnia)

The process of diagnosing pain and disease is very complicated, expensive, long, and worrying for Saman. He suffered from hip osteoarthritis and had to undergo surgery and joint replacement. Different doctors saw different reasons for his illness, and this made him confused and worried. He narrates the experience of communicating with the doctors and diagnosing the disease as follows:

Here at that time [Bukan], my doctor delayed me for three months and said he would do the surgery, but he didn't do it. I don't know why, but every time he delayed it for 10 to 15 days. Then, I had to go to Tehran [the capital of Iran]. Doctors said that you have hip wear, and you need to undergo surgery and joint replacement, but they didn't tell me exactly what is the cause of the disease. (Saman)

He continued the story and experience of his pain diagnosis as follows:

It was difficult for me to go to Tehran. The doctors said that this surgery can also be done in Urmia as well. I had surgery on both sides there, but this year, my left side started to hurt again. I lost my mobility, and I couldn't walk without cane. This time, I went to Tabriz to meet a neurologist. After the clinical examination, he referred me to the doctor who had operated on me and said that you are in same old trouble. You have the hip osteoarthritis again. I met my doctor. He scheduled me for surgery, and I underwent surgery again. After the surgery, he said that your joint was very stiff and the tissue was

inside your pelvis, so we removed the tissues. (Saman)

One of the primary effects of pain on chronic skeletal patients is loss of strength and physical ability, which gradually affects lifestyle and the process of living. Aziz, who has both a lumber disc and diabetes, distinguishes these diseases by their lack of strength and inability to perform physical activity:

Look! Diabetes is like cancer or maybe is worse. I have diabetes. If I don't diet, it can wear down me during a week, but lumbar disc isn't like it because if I want to do something, I can't at all. Yesterday, asked me to carry a box and I wanted to do it, but I couldn't. I didn't have daring and I said I can't. (Aziz)

This is also evident in Delnia's statements. "I didn't have this pain at that time, but it showed itself little by little. My body became powerless. It had no power and strength. I couldn't do the things. I used to do."

This condition causes the pain to continue and slowly penetrates all parts of life. Performing normal daily tasks, personal and social relationships, and mental and physical health changes cause patients to enter a new phase of life where they must accept pain as an integral part of life. The health deterioration is evident in Delnia's narration. She avoids loneliness. She likes caring for others and conversation. For a woman who has spent her whole life in the open, free, intimate environment of the village, breathing in a closed room is difficult:

We used to get together and talk to each other, work and go to the mountains, but the present life has taken away all the joys from me. With this condition of illness, traveling and meeting friends and family are almost impossible because a skeletal patient has his own special conditions; lie down, sit on the sofa, move slowly, etc. I wish my friends and children to treat me like they used to. I like to call the persons I love, to love them, to serve them, and to welcome them as the old days. I like to be busy all the time. I wish to please them, but I don't have the strength and physical ability. (Delnia)

These changes were more noticeable in Saeed than in others. "Although I used to always be ready to attend parties and celebrations, now I don't have the patience for these things and these places."

Aziz believes that illness makes life meaningless:

Sometimes I am invited to a party. I don't go because I can't sit comfortably or lay down. For example, I have to go to the bathroom, but I can't. I am not comfortable [due to physical conditions, he may need things or others]. It is very bad. Is this living? (Aziz)

Saman's narration of his current situation and living in pain is in line with the confirmation of Delnia's story. The pain has changed his life and has taken away his ability to do economic activity, which has affected other parts of his life:

I can't have a job and economic activity; this is a big responsibility that is for the head of the family. It's hard to not be able to do work. I don't have any fixed income or salary; I have to earn daily. You know when you are sick, you are like a person who lacks and his existence is incomplete. It means that he isn't a normal and complete person; he has a disability. He always feels that he is only alive. (Saman)

Losing socioeconomic status seems to mean losing the essence of life, something that separates them from society and family:

I still feel that I can work, and I like work. It is a duty of men, and they must work. You know if I don't work and my children do, it is

so painful. I don't like to be dependent on anyone, even my children. (Ali)

By connecting field observations with patients' narratives, the loss of social status and the inability to perform tasks due to pain and illness change other aspects of the patient's life. The person's authority derived from their socio-cultural status is lost when they lose their social status. This change is clearly visible in Saeed's life, and it has created special conditions for him. Living in pain has had a direct effect on his personal conditions, mental and physical health condition, family, social relationships, and has marginalized him.

My wife and children are also upset with my illness, and they involve anyway. Well, they have got tired because it's not for short time. Now, I don't care about anything. The cause of these is pain because this pain has disturbed my soul and spirit. It has become a tool that takes my power and authority away from me. Now, I don't have power. Somehow, my authority has decreased. My family don't count on me like they used to. Now, I feel it. I have this experience, if my relationship with my wife is normal, she is very good and happy and cheerful, but if I get bored because of my pain and I cannot be with her, she becomes rude and aggressive. I somehow feel she wants to say that you are good for nothing. (Saeed)

The Shadow of Death

The difficult and exhausting situation of living in pain led us to the third storyline, which shows the patient's future as uncertain and ambiguous. Concern about the future of pain and illness is clearly visible in Zahra's story:

Some time ago, a lady had sat next to me. She had a cane in her hand. She was walking very difficult. She wasn't much older than me. When I saw that scene, I got very upset. She was falling to the ground. I said that when will I find myself in this situation? I never had such a feeling before. (Zahra)

The uncertain conditions of the disease as well as the lack of social and family support have also created a vague and worrying future for patients. Masoomeh was one of those patients who, despite her poor physical condition and severe illness, was a very spirited and humorous woman. She was very frank during the interview. After hip surgery, her knee started to hurt. Having seven surgeries and her current condition had made life difficult for her family. She said:

My husband sometimes can't stand it and gets bored. He says, "Who can stand it like me? How long? How many years?" My relatives always tell me that nobody dies by pain of knee. Your heart and brain are healthy. You aren't disease. (Masoomeh)

This story is similar to Mina's. Mina's gaze was full of words. Everyone who saw her felt this. She was always quiet. She spoke very softly. If the researcher had not sat near her, he would not have been able to hear her voice. It was clear that there was a sadness in her life that she couldn't express. Mina's utopia is neither in the past nor in the future. She is confused and bewildered in the present. The illness has overcome her:

With this [disease] condition, my family expects me to be like the past. They don't care that I am sick or not. For example, they say, "What is the lumber disc? What is the disease? It is because of oversleep that your waist and feet have pain." Not only there is no companion who understands my pain and illness; but also, the others' tongue lashes have also doubled my suffering. (Mina)

Mahmoud's story leaves no doubt, and he openly expresses fear and despair about the future. He says, "If my illness gets worse, I am afraid that my family won't tolerate me anymore and leave me. Because I saw many

people who were sick and were rejected and are now in nursing homes."

With the continuation of pain, and the impossibility of returning to a pain-free state, the patient's relationship with his body and life changes. Pain becomes an inseparable part of the patient's life and mind. Apart from pain, the narrative experiences of participants reveal another uninvited guest, suffering, taking them beyond the illness and changes the future of life. The participants only feel alive and prefers death to living in pain. Saeed's life story clearly shows the shadow of death in life:

If it continues like this, I feel that I will be destroyed day by day...It is a gradual death. Every day this pain is killing me, which means I am slowly dying. Day by day I am physically weaker, and I have this feeling that my problems will increase as I get older. My pain has ruined my soul and spirit. I now have other pains besides physical pain. Like an addict, I got used to taking five milligrams of methadone every night to relax and sleep. If I don't take medicine, I can't sleep. I also have that severe and constant pain that is unbearable. If I describe my today life, I honestly don't have any goals. I'm so tired that at night when I sleep, I ask God and I say, "I wish I wouldn't wake up in the morning." Once I dreamed that I got into a fight with a soldier and he took my life with a volley and ended my life. At that moment, I was very happy. I said, "Oh, he killed me and I was relieved." Now, I'm not afraid of death, but I am afraid of getting worse. Against everything, I wish for death, and I wish I could die. (Saeed)

Discussion

Studies in the medical anthropology field show the suffering of patients who are exposed to chronic pain in daily life and determine the various aspects of pain and illness in social structure. This study provides insights into the pain and suffering experienced by chronic skeletal pain patients. Analysis of their narratives yields an overall storyline of the patient's past life situation, living in pain, and an uncertain future and despair. In fact, the narratives of patients with chronic pain describe the struggle where they feel their existence in danger (Råheim & Håland, 2006).

The first narrative, "Beyond Illness," shows how the experience of pain makes sense in retrospect because it is strongly associated with a difficult and hyperactive life situation. Past living conditions, lack of welfare facilities, different dimensions of poverty, intersectionality of environmental conditions, and potential determinants of health (Vedadhir et al., 2020) on the one hand, and lack of awareness and health literacy, and rejection of weak and sick people by the dominant culture of the society (Shamsi et al., 2019) on the other hand, has changed the current and future lives of patients.

The second narrative, "Living in Pain," takes us beyond pain where a pervasive suffering surrounds the patient's life. As Toye claims, the results show that patients have an ambiguous experience of healthcare (Toye et al., 2014). At first, patients are unable to diagnose and understand their pain and illness. There is no proper relationship between doctor (healthcare system) and patient. Most of the patients don't receive enough information about their illness and pain from their doctor. Also, the patient isn't given much role in the treatment process, and they are passive. The findings, similar to the results of Hadi's study (Hadi et al., 2019), show that patients with chronic pain have a poor quality of life and refer to disempowering impact of pain on all levels (MacNeela et al., 2015). Pain slowly changes daily routine life and affects the relationship between patients and others. Pain inevitably

comes to life itself and transforms the person's identity, leading to a set of physical, mental, psychological, and social consequences. The participants interpret their existence to be non-beneficial for the society, leading to isolation and depression supported by Newton's results (Newton et al., 2013), and participants enter into the stage of "mute suffering," believing that she/he is unable to speak in the face of one's own suffering and somehow lose her/his independence (Reich, 1987). The results in the present study are thus in line with Honkasalo, claiming that, except of pain and illness, the derived suffering led patients beyond pain and illness (Honkasalo, 2001); this has a serious impact on the pain experiences and identity of patients in a way that the life process for them has changed from "living" to "be alive."

The third narrative, "The Shadow of Death," shows despair and reluctance to continue living. The participants are suffering even in the absence of pain. Suffering means that pain is out of control (Schleifer, 2014), and the findings are supported by the results of Osborne and Smith (Osborn & Smith, 1998), and Smith and Osborne (Smith & Osborn, 2015), showing that patients tend to withdraw from social contact and constantly worry about the future. The passage of time and habituating with illness, frequent visits to the physician, taking medicine every day, doing physiotherapy every couple of months, along with past regret and sadness, and the community's view, will close the silver lining of the future. With the persistence of pain and the impossibility of returning to a pain-free state, the sufferer's relationship with their body and life changes. Suffering becomes an inseparable part of the patient's life and mind. When patients lose their endurance due to severe pain and suffering and are rejected by their family and society, they wish to die. These make them afraid of the vague future of their disease. Longer life with pain and suffering has no meaning for them, and death is the only way to salvation. According to Van Wijngaarden, the basic meaning of reluctance to continue living is understood as being trapped by a disability and unwillingness to connect to real life, which is characterized by a constant tension of lived life (Van Wijngaarden et al., 2015). Everyday experiences are inconsistent with people's expectations of life and their idea of who they are. As the feeling becomes more and more detached from life, the desire to end life intensifies. The results have revealed that today's treatment and care for persons suffering from chronic pain seems insufficient, resulting in increased suffering and health deterioration. It further enforces the need for a new, broader understanding and approach to the phenomenon of pain.

Implications for Health Behavior Research

The interpersonal experiences of the person in pain must be placed in the center of an analysis of chronic pain, and anthropology must infer the nature of pain experiences in the stories told by the narratives of those who are (Singh, 2017). It suggests that it is important to consider mental dimension and subjective experience of illness and pain in the daily life of patients in different cultural contexts. The outcomes of having chronic pain may collectively be more problematic than the pain itself (Nicola et al., 2022). The results of this study show that mental and physical health condition, social relationships, difficult and complicated conditions of living with pain, and the depressing suffering have covered the mentality of persons with chronic skeletal pain. With these words, it can be claimed that the constructed narratives from the voices of persons with chronic pain reveal one of the most appropriate meanings attributed to pain and suffering because the ability to tell one's story of chronic illness helps the sufferer create meaning in the experience (McMahon

et al., 2012). Therefore, in order to help persons with chronic pain and give meaning to illness, pain, suffering, and living with pain, the following items are important:

Increasing health awareness and literacy of persons with chronic skeletal pain can be effective in giving meaning to pain and illness while improving the future horizon of their lives. Previous studies (Ellis et al., 2015) emphasize the necessity of giving opportunity to patients to express their feelings about suffering. By sharing their experiences, patients can influence and challenge prevailing views on pain. In this regard, using the capacities of consultants in pain clinics as well as patients' associations (or NGOs) can be effective.

Family, as one of the most important support institutions, should play a significant role in dealing with chronic pain patients. In this process, as Toye points out, validating pain through meaningful and rational explanations, validating patients by listening to their stories, encouraging them to connect with a meaningful sense of self, and facilitating reconnection with the social world are the factors that families can make living with pain and illness meaningful and understandable for patients (Toye et al., 2021).

In terms of implications for clinical practice, in the results of this research, inconsistency between the attitude of doctors and the experiences of patients can be identified. On the other hand, the structure of the healthcare system in Iran has also played an important role in blurring the future of illness for patients. Accordingly, and to facilitate the relationship between the patient and the doctor, the following can be effective:

Given that the goal of medicine is to offer medical care to all people who seek it (Free, 2002), healthcare providers should play an important role in facilitating the appropriate doctor-patient relationship, in restoring and establishing an effective doctor-patient relationship, and in resolving the existing mentality about illness and pain. They should focus on the patient, not the illness. In this process, physicians and healthcare providers as treatment facilitators can play a role in giving meaning to life with pain and illness, and hope for the future. Because if patients think their pain is unbelievable, this is clearly a barrier to counselling (Dow et al., 2012).

It is important for physicians and health care professionals to listen to their patients' stories and realize that these acts of listening and telling may be part of the work of recovery (Kleinman, 1988). The physicians should share with the patients in the treatment process by giving information about their illness and treatment. Even if physicians cannot do anything about treating the illness and relieving the pain, they can certainly alleviate the patient's suffering with certain tricks and even a sympathetic relationship.

The training of person-centered relationship skills can help to solve the disability of some doctors in relation to psychosocial skills. Besides this, improving and reforming the structure of the healthcare system can lead to speeding up the process of diagnosis and treatment of the illness, restoring the patient's trust in the healthcare system, and having a better and more meaningful understanding of life in the shadow of pain and disease for the patient and their society.

Discussion Questions

How do chronic pain experiences shape the mental and physical health of patients, influencing their coping mechanisms and behavioral health choices? In what ways do the social determinants of health exacerbate the suffering and impact the health behaviors of individuals with chronic pain?

Considering the documented inconsistencies between doctor attitudes and patient experiences regarding chronic pain, how can health behavior interventions be designed to improve communication and empathy between these two groups? How can patient narratives inform a more empathetic and effective healthcare approach?

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