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The Health Seeking Behaviors and Perceptions of Iranian Patient with Osteoarthritis about Pain Management: A Qualitative Study

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ABSTRACT

Introduction: Pain is the main reason for patients with osteoarthritis (OA) to visit health clinics. Health seeking behaviors indicate unmet patient needs and lack of understanding of OA pain patterns. This study aimed to describe the experiences of Iranian patients with OA and explore their health seeking behaviors and perceptions on pain management related to osteoarthritis.

Methods: Using a qualitative approach, data was collected by interviewing 19 patients, 2 family members, and 5 health care providers from the in-patient and out-patient clinics, and physicians' offices. Data saturation was reached after 31 in-depth and semi-structured interviews (five second interviews). Data were analyzed by qualitative content analysis, using comparison, reflection and interpretation techniques. The criteria used to enhance rigor included credibility, transferability, dependability, and confirmability.

Results: Two main categories and six subcategories emerged from data analysis. The first main category included "adapting to the reality" which had three subcategories: Facing OA pain, seeking health care, and accepting pain as a part of life. The second main category included "behavior fluctuation" with three subcategory of role conflict, responsibility for self-care and, adherence to prescribed treatment versus self-treatment.

Conclusion: Care seeking behaviors for chronic pain sufferers are void of cultural, emotional, social and financial situation and patient expectations. Some misconceptions emerged about the health problem and its management, which may lead to negative attitudes toward treatment and therapists and finally lead to non-adherence to treatment. Patients need for education to enhance appropriate health care utilization.

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Introduction

Osteoarthritis is known as a common form of arthritis¹ and the most prevalent chronic joint disease² causing the highest rate of disability worldwide.^{3,4} Symptomatic osteoarthritis affects 10% of general population over the age of 60⁵ and accounts for 15% of all musculoskeletal primary care consultations for people age 45 and older.⁶ Prevalence of OA in

rural population of Iran is 20% and estimated to be more frequent in comparison with urban population.⁷

Current situation analysis predicts that population aging will be one of the greatest challenges of the health system in future. To meet these challenges, legislators, policy makers, and administrators have to focus on the health care needs of these population⁸ as

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well as the risks for developing chronic diseases.⁹ Impaired physical mobility caused by pain and joint stiffness,¹⁰ and reduced quality of life are among the most common manifestations of osteoarthritis.^{11, 12}

Pain is a major clinical symptom of osteoarthritis¹³ and the main reason for patients visiting the clinics.^{14,15} Chronic pain of OA is intensified with joint movement and weight bearing,¹⁶ impairment in mental health,¹⁷ social isolation, reduced self-esteem,^{18,19} depression,²⁰⁻²³ sleep disturbances,²² excessive use of healthcare services,^{24,25} and disturbed family and social dynamics.²³⁻²⁶

Disease related pain, may be fueled by the misperception of pain as a natural part of aging and considered unmanageable.²⁷ Only 50% of patients with OA visited their doctor for pain relief in 3 years and 64% saw a doctor only when they could no longer tolerate the pain. Elderly patients commonly consider alternative treatments such as home remedies for unrelieved persistent pain. These results support findings that most people with OA tend to rely on self-treatment to reduce pain²⁸ when their prescribed medication deem ineffective.²⁹

Health seeking behavior is significantly influenced by culture, religion, and socioeconomic status. Every culture has norms, expectations, accepted practices, values and beliefs as a foundation for health seeking behavior.³⁰ Several studies have indicated that health beliefs can influence adherence to pain management recommendations.³¹⁻³³

Studies have shown that interpersonal relationships impress illness behavior, care seeking and attachment styles in patients with chronic pain³⁴ but they did not clarify how. Moreover, studies on adherence to treatment have generally focused on pharmacotherapy and their effectiveness for pain management.³⁵⁻³⁷ Although few trials have been done on mud therapy, traditional cupping therapy, herbal therapy, leech therapy, and acupuncture in pain relief,³⁸⁻⁴¹ they didn't including patients' perception and behaviors.

This study aimed to describe the experiences of Iranian patients with OA and explore their

health seeking behaviors and perceptions on pain management related to osteoarthritis.

Materials and methods

A qualitative design was used in this study. Qualitative research methods are based on a common intellectual foundation that look at the ways that people make sense their experiences to understand, describe and interpret social phenomena in the world around them.⁴² Although there was some previous studies in OA pain management, but knowledge about the health seeking behaviors as the phenomenon the study was scattered and segmented. So to build a deep understanding for describing phenomenon in a conceptual format and inductive content analysis was chosen for analyzing data.⁴³

Patients with OA were selected from three teaching hospitals in Tabriz (Imam Reza, Shohada, and Sina) and five rheumatology out-patient clinics (Sheikhoraeis, Atyeh, Sina, Shohada, and Shahid Mahallati) for their centralized location and easier access to the patients. In order to access to patients who diagnosed OA but didn't choose health services for managing their problem and prefer to practice just self -treatment, we conduct snowball sampling.

Participants in a qualitative study should experience the conditions, environment, events and incidents of the phenomenon in order to provide accurate information and to be able to reflect on their experiences with interest.⁴² Participants with different treatment modalities and illness severity were included in study to elicit diverse experiences with OA. Data were collected by using semi-structure and in-depth interviews to obtain deep insight into participants' and simultaneously analyzed until data saturation was reached and no new concept appeared.⁴³ Qualitative data is commonly obtained via semi-structured interviews to allow free expression on personal experiences and less restricted accounts.⁴⁴

All interviews took place in a private setting and arranged to be convenient for the participants at their homes, work or a

healthcare facility and at a time chosen by the participants.

Thirty one interviews were conducted with twenty six participants (19 patients with OA, two family members, and five health care workers) were recruited and interviewed from the hospital in-patient departments, out-patient clinics, physician's offices, or their homes based on purposive sampling and informed of the study objectives and upon their verbal agreement, a written informed consent was presented and voluntarily signed. Second interviews were done as a follow up with five participants. The interviews began with an introduction to obtain an informed written consent and continued with asking each participant to explain a day living with OA and what was their perception of OA pain and how it should be managed. Probing questions helped gaining more details to broaden understanding of OA phenomenon.

The interviews lasted 15-90 minutes. Participants were asked general open-ended questions about their experiences with OA as a disease, pain management and health seeking behaviors. Researchers used the snow balling method for identifying participants based on the recommendation of other selected members.

The interviews were conducted in Azari and Persian languages speaking peoples, tape recorded and transcribed verbatim. The Azeri interviews were translated into Persian with the help of an Azeri interpreter and back translated to illuminate hidden meanings before being transcribed. To assure accuracy, and assure extraction of the real essence from Azeri language, 3 bilingual reviewers reviewed and checked codes. Then collected data and interpretations were shared with participants to confirm the coding designation and later rated by colleagues. Research team verified transcribed coded data in a group discussion. The content was analyzed in Persian language and later translated into English. With every new code emerging from the text, transcribed data were updated in the codebook and reviewed again to verify and identify at least one quote that illustrated the

themes in the dataset and to make it easier to read the quotes before being translated into English by 2 bilingual medical terminology expert translators.

Data were analyzed using qualitative inductive content analysis approach. Upon the first interview data were simultaneously analyzed until saturation was reached.

Transcribed data were read to reach an overall understanding of content. Then interviews transcription was discussed by co-authors several times to clarify and gain a sense of whole. The interviews were read word for word and the impressions were jotting down. The interview text was divided into meaning units by words, sentences, or paragraphs based on participants' experiences. Condensed meaning units of the contents were extracted and grouped into categories and subcategories by comparison, reflection and interpretation techniques.⁴⁴ Researchers continuously reviewed and rechecked the coded data for accuracy and clarity.

The criteria used to enhance rigor included credibility, transferability, dependability, and confirmability.⁴³ Credibility was assured by researchers' long-term involvement, ongoing presence and close observations at each clinical setting. Researchers and participants verified data accuracy through a second interview and interpretation of findings were reviewed by an external auditor. Dependability was established by consistent data assessment and documentation to identify contrary information. Confirmability was satisfied by a lengthy report outlining the research process for an audit. Transferability was confirmed by asking a group of uninvolved individuals to compare and contrast the research findings with their own OA experiences. Participants represented a vast demographic population in the northwestern part of Iran.

Results

Demographic characteristics of patients with OA are presented in Table 1. Analyzed data revealed two main categories and six subcategories for health seeking behavior: I. Adapting to the reality followed by

subcategories of: 1) Facing OA pain; 2) seeking healthcare; 3) accepting pain as a part of life; II. Behavior fluctuation in self-care maintenance followed by sub-categories of: 1) role conflict; 2) responsibility for self-care; 3) adherence to prescribed treatment versus self-medication.

I- Adapting to the reality

1. Facing OA pain

Osteoarthritis starts with perceptions of unusual symptoms such as pain, weakness and joint instability. Paying attention to these symptoms can vary in patients depending on the personal context (attitudes, beliefs, and emotions) and living conditions. In early stages of OA, pain severity and other health symptoms were not perceived as serious for most patients and their family members. A patient with progressive knee OA indicated: *"At first, when I walked, my left knee was unstable and I walked funny. I was employed and my knee felt strange, swollen and painful. I was diagnosed with OA and started with medical care"* (P1, Female, age 71).

The initial shock of learning about OA diagnosis, patients experience the stages of denial, anger, positioning, depression and acceptance. Denial is associated with the initial indifference to the problem and attributing it to multiple factors for justification and intentional forgetfulness. An employed woman with long history of progressive OA indicated:

"At first, I thought that life pressure makes these pains... But later I saw that they were irrelevant to these and my Osteoarthritis began to progress" (P3, Female, age 72).

2. Seeking Health Care

Patients start looking for help depending on understanding the disease nature, symptoms, the risk for disability, the ability to control the disease progress, previous exposure to problems and acquired experiences about the disease, the pain tolerance and disease acceptance as a health problem.

In the early stages of disease, pain was temporary and less attention was paid to the problem and later, pain intensity caused to

take action and do something. Some of them used herbal treatments and other remedies for pain relief.

As time passed and OA progressed; patients and their family members concentrate more on the importance of the disease and developed a different view of the disease symptoms exacerbating affecting daily life. An OA patient's daughter who caring for her mother with history of advanced OA for 22 years said: *"Busy people focus on future not illness. But, aging help us realize the importance of health and family support"* (P4, Female, Age 56).

A number of participants ignored early warnings and avoided follow up visit to their doctor.

Participants with a family history of OA were able to identify early signs and symptoms of the disease and sought healthcare sooner. A patient with OA history in her family member indicated:

"I noticed the signs, because my mother has OA and she is crippled. Her feet and ankles are inflamed and contorted. I don't want to be crippled" (P7, Female, Age 58).

Elderly and more educated participants believed in preeminent medical authority and considered regular doctor visits, precise clinical assessments and accurate diagnosis to be crucial for adequate disease management. Family members' view point influenced patients' health seeking behavior.

3. Accepting Pain as a Part of Life

When patients accept and believe that there is no cure for OA, pain becomes an integral part of their lives and began to tolerate it with a positive attitude. A patient with long history of neck and shoulder OA indicated:

"At first I was sad, but soon took action, learned about OA and accepted that it was untreatable. I chose to be proactive and manage the OA pain" (P1, Female, Age 71).

Participants who managed their OA pain described their experience as relative comfort through tolerance. By accepting the pain as a part of life they found temporary relief.

"I thank God when I feel better and I can walk without pain. I take care of myself with light

exercises to prevent its progress and reduce pain” (P2, Male, Age73).

II. Behaviour fluctuation in Self-care maintenance in OA pain management:

1. Role Conflict

Despite the recommended treatment to prevent exacerbation of OA symptoms and delay the disease progress, participants struggled with role conflict within the family. Patient’s expectations for personal care were unmet due to role conflict.

“When I was younger, I neglected my health to support my family for survival. It was my role to take care of them. There was no time for me and my health” (P3, Female, Age72).

Participants reflected that as time passed, they experienced more pain and disabilities, their disease progressed, and the support provider became a support recipient. So they began to avoid and resignation away from all the opportunities that cause pain. Some applied for disability compensation or government assistant, others chose early retirement and majority moved toward social isolation.

“With knee pain I can’t go anywhere. In summer I walked across the street, just sat on the sidewalk and cried. Now, I stay home and my family is worried about me” (P4, Female, Age56).

2. Consistent Responsibility for Self Care

Majority of patients who visited doctors were instructed to protect their joints and prevent further damage by taking their daily medication dose and following protective measures regularly, they would forget or ignore the instructions and resume their daily activities with slightest pain relief. Participants viewed pain relief as getting “back to normal” and for unknown reasons avoid follow-up measures.

“Unfortunately, we care for our joint and follow advice, soon forget or make excuses. We wait for the pain to return before taking OA seriously” (P11, Male, Age 39).

Recurrent pain would indicate seriousness of the disease and importance of consistent treatment adherence. Only a few of the participants believed that OA was a life-long disease and assumed personal responsibility for self-care.

3. Adherence to Self-Medication versus Prescribed Treatment

Some of the participants managed their initial pain by self-medication without medical consult.

“I managed the pain with knee massage, moist heat and compress; I slept with pillows under my knees and heels and did water exercises. Swimming reduced my pain and I didn’t have severe pain” (P11, Male, Age39).

Denial of chronic and progressive nature of disease can lead to the creation of unreasonable expectations in patient (request for cure) and given that it is not possible to achieve this goal, patients exhibit compulsive behaviors by visiting multiple doctors without following their treatment plans, referring to non-specialized therapists and seeking therapeutic strategies from relatives and other patients with OA. Pain management for OA from the perspective of specialists is intended to relief pain, reduce symptoms and improve mobility, in order to avoid permanent disabilities, while patients live with hope for a “cure”. A Rheumatologist with 10 years’ experience indicated:

“I have seen patients go to many doctors and get multiple prescriptions. They use each medication expecting a miracle. They stop when there is no pain relief. With inconsistent treatment they go another doctor” (H4, Male).

Once participants recognized that changing doctor was not helpful, they engaged in self-medication with a wide array of treatments. In some cases, participants had a sense of mistrust and desperate for some pain relief. They continued to search for a “magic pill” for their relentless pain.

“Patients look for a miracle with different prescriptions such as Naproxen, Ibuprofen, Aspirin or Acetaminophen. Depending on the patient’s GI

Table 1. Demographic characteristics of participants (patients with OA)

Variable	N (%)
Gender	
Male	2(10.5)
Female	17(89.5)
Occupation	
House hold	10(52.6)
Retired	4(21.1)
Governmental	3(15.8)
Nongovernmental	2(10.5)
Affected area	
Knee	12(63.2)
Knee & Shoulder & Neck	2(10.5)
Knee & Lumbar	3(15.8)
Knee & Shoulder & phalanges	1(5.3)
Knee & Neck & phalanges	1(5.3)
Marriage status	
Married	16(84.2)
Single	1(5.3)
Widowed	2(10.5)
Age^e	
Min: 39, Max: 75	57.94(11.02)
Disease period^e (years)	
Min:1 , Max:21	13.94(6.08)

^eMean (SD)

Discussion

It was found that mild pain and early symptoms were often ignored despite medical diagnosis. This means patients often refused follow up visits and medical instructions and began self-treatment to relieve pain. The attitudes of family members who are the main decision makers, and the experienced elders, who are the source of narrated traditional treatments in Iranian families, has the main role in health seeking behavior. Patients with OA searched for a "normal state", took inconsistent medical treatment with painful episodes of and overtime, disease progression and symptom exacerbation changed their views toward OA as a chronic condition.

Sale and colleagues wrote, "Subversion" or failure to accept pain and restricted daily activities is an elderly coping response to avoid social and psychological isolation as an essential part of life.³² Mature

individuals seek independence and their health seeking behaviors largely depends on the disease severity and loss of mobility.^{45,46} Participants in this study did not visit a doctor until it was absolutely necessary.

Turkiewicz and colleagues and Prasanna and colleagues, reached the similar conclusion as patients delayed seeking medical attention.^{47,48}

Some studies showed a direct association between pain severity and visits to healthcare facilities^{25,49} as well as pain-related disabilities and the use of healthcare services.⁵⁰ Patients in our study defined pain based on its severity and clinical manifestation such as disability. Those with a family history of OA were better able to detect early signs and symptoms and understood the importance of seeking specialized medical care at the first stages of the disease. Hart and colleagues noted that nonspecific diagnosis was the most

common reason for visiting a primary care clinic.²⁵

Similar to our findings, Manchikanti and colleagues (2013) reported that chronic pain led to an increased number of doctor visits at a wide range of healthcare facilities⁵¹, especially when pain and disability affected patients socially and economically.⁵²

Addressing the psychological aspects of pain could improve emotional, social, physical functioning and the quality of life.⁵³⁻⁵⁵ Experimental clinical studies have demonstrated that acceptance of pain can lead to greater pain tolerance compared to cases with mere focus on pain control^{56,57} and reduction in analgesic dose and doctor visits.⁵⁸

We found that initially patients resisted acceptance of their chronic condition and later looked for alternative methods to relieve pain. Some studies showed alternative methods such herbal therapy could be used as an alternative to the NSAIDs in OA patients.³⁹

In some instances elders don't perceive pain as abnormal or unexpected condition in aging. Many older adults pay attention to social expectation rather than their physical needs because there are some cultural barriers especially for male to complaint of pain⁵⁹ and disability. Then, instead of fighting to conquer their pain, they opted to increase their "pain tolerability level" and "become friendly with their pain". In their study, McCracken and Vowels reported that acceptance of chronic pain means an individual stops unsuccessful attempts to eliminate pain and, instead participates in a goal oriented worthy activity for personal benefits and could be more successful if patients could come to terms with their pain, depression, disability, pain-related anxiety, physical and vocational functions instead of using different coping measures.^{58,60}

In our study, participants perceived pain control as achieving relative comfort in physical mobility. They realized unrelieved pain had to be endured. Bhana and

colleagues also found that all pain sensations could not be controlled, and pursuit of a pain free life was unrealistic.⁶¹

Pain was considered as an integral part of life and better accepted by some of the participants in this study. We found as the disease progressed, patients experienced a role shift from being the support provider independent adult to a support recipient dependent patient. Such a major shift in role changed family dynamic and demanded significant personal and family adjustment for great expectations from both sides. Patients experience social isolation, unemployment or early retirement. Williams and colleagues, asserted: patients with chronic pain cope through social isolation, role modification, and marital discourse, sexual dysfunction, feelings of anger, anxiety, and resentment.⁶²

Participants in this study attempted self-treatment without consulting a doctor and even after seeing a doctor, many of them did not follow the treatment plan due to irregular manifestation of disease symptoms. Most patients with chronic pain, wished to spend no more than necessary time at their physicians' office and preferred to self-manage their illness.⁶³

Self-treatment could mask other serious conditions for unsafe dosing and unrecognized side-effects.⁶⁴ According to a traditional view in families in Iran, traditional home remedies such as herbal therapy are considered as a safe treatment and free of side effects for pain relief.

Recent studies suggested that most of arthritic patients use alternative therapy because the public view about herbs as natural and risk free components that are easily available.⁶⁵ Whereas longer trials are needed to explore efficacy and safety of herbs for treatment of osteoarthritis.⁶⁶

We learned that participants engaged in daily activities with the slightest pain relief and at times, to over extortion level without treatment adjustment. McCracken and colleagues had similar findings, whereby patients who accepted their disease were

able to participate in enjoyable activities and hypothesized that disease acceptance sets the tone for behavior modification and a healthier social, emotional, and verbal interactions.⁵⁸

Postponed and interrupted treatment often required a higher dose for a longer duration to control the pain. Inconsistent adherence to treatment according to our findings led to changing doctor by over 50% of pain sufferers. Specific reasons for changing doctor included lack of willingness to treat pain more aggressively, failure to take the patient's pain seriously, and perceived lack of knowledge about pain management. Researchers found gaps in knowledge, negative attitudes toward prescribing opioids, inadequate assessment skills, and hesitation to prescribe stronger pain medication as barriers encountered by patients.⁶⁶⁻⁶⁸

According to Butow and Sharps, "models such as health belief model, self-regulation theory and the theory of planned behavior suggest two key factors for promoting adherence: (1) good health care providers communication and (2) interventions that are tailored to individual reasons for non-adherence. Thus, although treatment of chronic pain is challenging, good communication between health providers and patient can promote adherence and improve outcomes".³¹

This study was approved by the Regional Ethics Review Board at Tabriz University of Medical Sciences (Ethical Code: 91118). Participants initially offered verbal consent for tape recording of conversations and soon after, signed a written informed consent detailing the study goals and objectives, risk free, voluntary participation, and liberty to withdraw at any time without obligation. The informed written consent highlighted respect for anonymity, privacy, confidentiality, and data security in a password protected digital file.

We recruited patients from various parts of the population for an unbiased representation and identified diverse

perspectives to understand and describe the process and variation in the health seeking behaviors. However, what our participants reported and described does not represent the general public and we cannot foretell how specific they approach their chronic conditions.

Conclusion

This study showed that health care seeking behaviors for chronic pain sufferers are influenced by cultural, emotional, social and financial needs and patient expectations. Our study showed some misconceptions emerged about the health problem and its management in OA patients, which may lead to negative attitudes toward treatment and therapists and finally lead to non-adherence to treatment. Results of this study could help health care providers to understand patients perception about OA pain and its nature as well as recognize their coping patterns, decision-making and treatment adherence or dissociation.

Healthcare policy makers have to focus on improving health literacy by patient education to improve adherence to treatment and self-management in OA patients

Nurses are in the first line of cognitive and behavioral interventions in Iran and have a unique and critical role. They could arrange and implement programs for patient empowerment, educate several pain management strategies, emphasize adherence to medical advises, coordinate multidisciplinary interventions and monitor the patient responses to treatment.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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