A qualitative study on patients with knee osteoarthritis to evaluate the influence of different pain patterns on patients' quality of life and to find out patients' interpretation and coping strategies for the disease

Keith K.W. Chan, Loretta W.Y. Chan

Musculoskeletal Physicians, Hong Kong

Abstract

The objective of this qualitative study of patients with osteoarthritis (OA) of the knee was to evaluate the influence of different pain patterns on their quality of life and to investigate their interpretation and coping strategies for the disease using patient interviews. Patients were recruited by convenience sampling in a private general practice clinic in Hong Kong. Those screened positive for OA of the knee were asked to self-evaluate their average pain score and classify the severity of their OA before attending a semi-structured interview by a research assistant. Twenty patients were interviewed and 98 codes were identified. The content was analyzed independently by two researchers who were not doing the interviews. Codes and themes generated were analyzed based on the grounded theory. A wide range of symptoms was described by patients with OA of the knee, in which pain was the most prominent symptom. Most patients (80%) described two different types of pain, mechanical and inflammatory pain, each presenting with a different pain quality and onset pattern. Most patients self-graded their OA severity at a level higher than their corresponding pain score, indicating that there may be other variables that patients would consider during self-evaluation of severity. More than half of the participants seek medical assistance late because their health-seeking behavior was affected by their perception of the problem, concern, and expectation from treatment. The study findings can help healthcare providers to understand and be aware of the existence of two pain patterns, mechanical and inflammatory pain in knee OA, as well as to appreciate the great variations of symptoms, the different perspectives, and the different coping and health-seeking behaviors among knee OA patients during their management. Finally, this study also provides a useful basis for further research on topics like factors that affect patients' self-evaluated disease severity and efficacy of interventions specific for the two different pain patterns associated with knee OA.

Introduction

Osteoarthritis (OA) of the knee is a common problem throughout the world. According to statistical data from the World Health Organization (WHO), the worldwide age-standardized prevalence rate[1] per 100,000 world standard population in 2000 was 1,770 for males and 2,693 for females.[2] The condition is more prevalent among the elderly with up to 40% of people aged over 70 years being affected.[3] Similar findings were reported in Hong Kong in a study conducted among 38,000 elderly people aged 65 years and above who attended the 18 Elderly Health Centres in Hong Kong for health assessment in 2008.[4]

For such an important health issue, different global assessment tools have been developed for evaluating the severity of knee OA symptoms and its impact on quality of life. The Western Ontario and McMaster University Osteoarthritis Index (WOMAC) is a disease-specific scale most commonly used for assessment of pain, stiffness, and physical function associated with OA.[5-7] The Medical Outcomes Study 36-item Short Form Health Survey (SF-36) assesses the pain, physical health, and mental health among patients with chronic diseases with emphasis on assessment of health-related quality of life (HRQOL).[8,9] The Lequesne Algofunctional Index is an outcome measurement instrument for hip and knee diseases assessing the pain, the maximal distance walked, and the activities of daily living.[10,11] Among all these knee OA assessment tools, pain assessment is the major subject of concern.

A local study done by the first author on comorbidities of knee OA patients found that 4.6% of the patients recruited in the study, using the diagnostic criteria of knee OA established by the American College of Rheumatology (ACR), had signs of joint inflammation in the form of palpable warmth of the synovium.[12] This implies that although the majority of knee OA patients have pain from joint loading or joint motion (mechanical pain), a minority of knee OA patients have pain from joint inflammation (inflammatory pain). Such differentiation is important as different pain patterns may affect patients' quality of life differently, and the management of mechanical and inflammatory pain is theoretically different. However, none of these knee OA assessment tools gives an account on this aspect.

The main objective of our research is to study knee OA patients' awareness of these two types of pain patterns and how the mechanical and inflammatory pain are affecting their quality of life. The second objective is to get further information on how knee OA patients perceive and adjust to the impact of the disease, what they worry about, and what they expect from the treatment. It is hoped that with this information, healthcare providers may be more aware of the problems, needs, and expectations of patients with knee OA, and understand their health-seeking pattern and behavior, so that the management focus and resource allocation will be better positioned.

Correspondence: Keith KW Chan, Room 1201, 12/F, City Landmark I, 68 Chung On Street, Tsuen Wan, Hong Kong. E-mail: drkeithchan@gmail.com

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Materials and Methods

Qualitative methods were used because we were interested in how patients viewed OA of the knee and its impact on their lives. To avoid interviewer bias, an independent research assistant conducted all interviews in a primary care clinic. Patients were recruited using convenience sampling.

All patients presenting to the clinic were screened for a history of knee pain by the receptionists. During the consultation, those with a history of knee pain were screened further by the attending doctor for clinical features of knee OA, using the diagnostic criteria established by the American College of Rheumatology (ACR; Appendix 1).[13] Patients who were diagnosed as having knee OA were asked to self-evaluate their average pain score

using a 10-point visual analogue scale (VAS). Patients also self-classified the severity of their knee OA as either absent, mild, moderate, severe, or very severe before attending a semi-structured interview, which had a standard set of questions as the framework (Appendix 2).

All the interviews were conducted in Chinese. The sampling was continued until the research assistant found the content of further interviews was repeating itself. The interviews were audio-taped and transcribed in Chinese. The content was analyzed independently by two researchers, one male and one female, who were not doing the interviews. Ideas and themes generated from the interviews were analyzed based on Glaser and Strauss's grounded theory.[14-16] From the data collected, codes were extracted from the transcripts by the individual researcher on the basis of what the interviewees discussed, as well as the issues that the researcher believed to be salient based on his/her prior knowledge and theoretical understanding of the pathophysiology of OA of the knee. The results of the analyses were compared and discussed between the two researchers using the constant comparative approach[17] until a final version of the codes was agreed. The codes were then grouped into threads based on the descriptive text derived directly from responses to the interview questions, while those more interpretive ones were based on data from a number of questions. In order to make the threads more manageable, related threads were grouped into a construct.

Results

A total of three interview sessions was carried out over three days between September and October 2009. One session was held on a weekday morning, one session on a weekday afternoon extending into the evening, and one session on a Saturday morning. This arrangement was aimed at including more people of broad socio-economic status. A total of 20 interviews was conducted and each interview lasted for about an hour. The characteristics of the interviewees are shown in Table 1. There was a predominance of females (66%) with most (80%) interviewees being over the age of 50 years. Nearly half (46%) reported having OA of the knee for more than 10 years. Nine patients (45%) self-evaluated their pain score to be <4 and another nine patients (45%) reported a pain score of between 4 and <8. The mean pain score of all 20 patients was 4.725 (standard deviation, 2.16). OA was considered severe in seven patients (35%), moderate in five patients (25%), mild in four patients (20%), and very severe in the remaining four patients (25%). A total of 98 codes was identified from the transcripts, which were classified into 20 threads and then grouped into 11 constructs. (Table 2).

Table 1. Characteristics of participants.

Characteristics	No. of informants (n=20), N (%)
Sex	
M	7 (35)
F	13 (65)
Age (Mean 57.05, SD 10.79)	
>60	8 (40)
50-60	8 (40)
40-50	3 (15)
<40	1 (5)
Duration of disease	
>=10 yr	9 (45)
<10 yr	11(55)
Patient's self-scoring of knee pain in visual analog scale (Mean 4.725, SD 2.16)	
1 to <4	9 (45)
4 to <8	9 (45)
8 to 10	2 (5)
Patient's self-perceived OA severity	
Absent	0 (0)
Mild	4 (20)
Moderate	5 (25)
Severe	7 (35)
Very severe	4 (20)

Table 2. Main categories identified from the interview.

Constructs	Threads	Codes
Health-seeking behavior	Reasons for treatment	Reasons for consulting doctors
	Treatment chosen	Ignore
		Different treatments sought
		Primary care providers (Government/Private)
		Orthopedic specialist
		Physical therapist
		Traditional chinese medicine / bone setting related
	Factors affecting choice of treatment	Doctor shopping
		Efficacy of treatments
		Monetary costs of treatments
Self-perceived causes of OA of the knee	Self-perceived cause of OA of the knee	Self-perceived cause of disease
Description of symptoms	Signs and symptoms	Pain
		Severity
		Duration of pain
		Swollen
		Change shape
		Sound
		Tight / stiff
		Weak / numb
		Cannot bend knees
		Inflammation
		Unpredictable
	Progression of symptoms	Progression of symptoms
	Factors affecting the symptoms	Factors of temperature and weather

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Constructs	Threads	Codes
Pain pattern - mechanical pain	Mechanical pain	Pain on weight bearing: Walk stairs and slopes Carry heavy stuff Stand up Stand up after sitting for a long time Stand for a long time After running After long walk / walk more, suffer more Pain on bending / squat Pain on foot lifting Pain caused by joint movement Pain after legs kept still for a long time
Pain pattern - inflammatory pain	Inflammatory pain	Awareness of inflammatory pain Awareness of difference between usual pain and inflammatory pain Duration of inflammatory pain Severity of problem Frequency of inflammation Understanding reasons for inflammation Do not know / do not pay attention to Misplacement of joints / sprain Walk, stand, or move for too long Affected by other parts of body Progression from usual pain Weather related Management
Impacts on physical activities	Impacts on daily activities	Declining ability in walking and standing Difficulty in dressing Difficulty in going to toilet and taking shower Need help for standing up from sitting Difficulty in ascending and descending stairs Woken up by pain during sleep Need walking stick / afraid of falling down Feeling tired easily Inconvenience in general No big impact
	Impacts on doing housework	Cooking Difficulty with buying food Difficult with cooking because cannot stand for too long Cannot cook for family Do not want to cook Other housework Spend more time on doing housework Cannot manage to do housework Do not want to do housework Very tired after doing housework Still have to do it even if it hurts
Impacts on social activities	Impacts on recreational life	Limit the place for sightseeing when traveling Limit the choice of plane seats when traveling Reduce frequency of shopping
	Impacts on work life	Feeling tired easily at work Feeling inconvenient Less efficient Need to take sick leave Need to quit job Fewer business trips / do less business
	Impacts on family life	Difficulty with carrying kids Difficult with playing with grandchildren Going out less frequently with family Dependence on family Family members spending time to bring them to the doctor Easily get annoyed and argue on minor things with the family / loved ones No impact

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Constructs	Threads	Codes
	Impacts on social life	Unable to wear high-heel shoes or fashioned shoe Problems with taking public transport Need to be accompanied by others when going out Prefer staying at home / going out with friends less frequent No impact as friends are considerate No impact as can talk on phones
Impacts on mental health	Psychological symptoms	Unhappy Worried Annoyed / Easily be irritated Hate oneself Want to hide away from the crowd Depressed once thinking of the necessity of frequent medical attendance Afraid that cannot work anymore Feel useless Feel like a disabled person People do not understand them Dislike to be helped Nothing they can do Accept it as many people have same problem Accept it as it's natural Feel better if know the cause and treatment of problem and vice versa
Adjustments	Daily activities	Exercise Doing less / stop / change to different exercise Do exercise to reduce pain or strengthen muscle Going out Walk / go out / climbing stairs less frequent Need to be accompanied when going out Take more rest Use stick or assisting facilities or kneepads Take painkiller before going out Avoid taking stairs / take fewer stairs Adjust movement / activity according to condition
	Self care	Daily care Concern about weight issues Change the style of shoes Beware of diet Do not carry heavy stuff Take more care of oneself / pay more attention to one's health Do less housework, hire people, help & support from family members See doctor / take prescribed medicine Other means of Self-management Ice Thermal treatment Massage, with ointment or other OTCs Rest the legs Folk practice Sources of knowledge of self-management Doubts during self-management Efficacy of self-management
Major concern	Major concern	Cannot walk / getting worse Cannot do exercise Cannot work Need someone to serve oneself Have to have knee replacement surgery Negative effects of drugs / rely on drugs
Expectations from treatment	Expectations from treatment	Reduce pain/improve the condition Be cured Prevent further deterioration Get more information about the problem
Total	20	98

Health-seeking behavior

Most patients (55%) chose to seek medical assistance late in the course of illness despite experiencing knee OA symptoms for a long time. Reasons for the delay in seeking help included accepting symptoms as part of the aging process, the intermittent nature of symptoms, and fear of facing the reality. Patients only started seeking medical help when their social lives or daily activities were affected. The choice of medical assistance was variable, ranging from primary care providers, orthopedic specialists, physical therapists, and traditional Chinese medicine doctors to bone-setters. Factors affecting their choices included perceived treatment efficacy and treatment cost. In many cases, patients started doctor shopping because they were disappointed with the results of their current treatments.

Self-perceived causes of osteoarthritis of the knee

A proportion of patients (35%) attributed the cause of their OA to overwork at a young age. Others attributed it to rheumatism, menopause, and being overweight.

Description of symptoms

A wide range of symptoms was described by patients with OA of the knee in which pain was the most prominent symptom. Other symptoms described were swelling, deformity, tightness or stiffness, weakness or numbness, presence of sound on movement, inability to bend the knee, etc. The pattern, duration, and progression of symptoms were highly variable among patients. However, about half (55%) described the influence of weather on their knee pain, with exacerbations associated with cold wind, rain, and increased humidity.

Pain pattern and coping strategies – mechanical and inflammatory pain

Most patients (80%) described having two distinct patterns of pain, mechanical and inflammatory pain. The mechanical pain described by patients was pain resulting from weight-bearing and knee movements, such as knee bending and foot lifting. This pain would become more severe with increased mechanical load, such as when lifting heavy weights, or walking up stairs or a slope, and would disappear after resting. Most patients (65%) described the pain as sharp and usually precipitated by knee movement after prolonged inactivity; for example, getting up after sitting still for a long time. This sharp pain would gradually ease after a few minutes of gentle walking or by self-massaging the knee.

In contrast, the onset of inflammatory pain was less predictable. It could be triggered by weather changes, prolonged walking, a minor sprain, or from misplacement of the feet during walking. Sometimes, inflammatory pain occurred as flare-ups in the form of exacerbated pain with the background of mechanical pain. It was described as a burning pain that could persist for days without treatment. The knee might become swollen and hot and the pain was sufficiently strong to impact on daily activities and sometimes even made walking difficult. Patients found resting and ice packs helpful, but most help came from taking analgesics, especially non-steroidal anti-inflammatory drugs (NSAIDs). The frequency of inflammatory pain was highly variable, from once every few months to once every few weeks. Sometimes the inflammatory pain might have a relapsing pattern, with the pain regressing gradually and relapsing again a few days later. This pattern could persist for three to four months. Irrespective of whether pain was mechanical or inflammatory in nature, patients would avoid events that would trigger or aggravate the pain or take analgesics before the event as a preventive measure.

Impact on physical activities

The impact on physical activities was dependent on the severity of the OA, which ranged from no impact and feeling tired among patients with mild OA, to requiring walking sticks and assistance on standing up from sitting in those with moderate OA, to having difficulties in attending to their daily living among those with severe disease. As the majority of patients with OA were female, the impact on household activities was also significant. Some found shopping at the market difficult or standing during cooking exhausting. Although some continued to cook despite the pain, they needed more time to finish the job.

Impact on social activities

Social activities including recreational life, work life, family life, and social life were affected in patients with OA of the knee. Depending on the severity, the impact varied from no impact, to cutting down the participation in social activities, to total abstinence. With disease progression, going out became difficult for some patients and taking public transport was usually a problem. Patients often needed to limit their choice of social activities, depending on the availability of suitable transport facilities and the walking distance to the destinations, or to give up their recreational or social activities altogether. Working patients were sometimes forced to change their jobs or even to opt for resignation or early retirement. Grandparents might have to give up looking after their grandchildren. Patients were often reliant on support from the family.

Impact on mental health

Knee OA was associated with negative feelings, depression, worries, fear, social withdrawal, and isolation. Some patients became annoyed and irritable thinking that people around them did not understand them. A significant proportion of patients (40%) expressed that a lot of their stress came from the unpredictability of the symptoms, the uncertainty of the progress of OA, and the ineffectiveness of the treatments. Despite the overwhelming negative expressions and feelings among patients, some patients in our study accepted OA as a natural degenerative process and disliked being helped.

Adjustment

Patients adopted various coping measures including lifestyle modification and physical treatment to improve their daily activities. Some forms of self-management were reported by all interviewees. Patients learned their coping strategies from the media, Internet, physical therapists, doctors, and health professionals, as well as from fellow sufferers. Patients found self-management useful and efficacious. This included rest, simple physical therapy like ice therapy, thermal treatment, and massage, and use of topical agents or other over-the-counter medications.

Major concerns

The major concerns expressed included disease progression, loss of function, inability to walk, need to be taken care of, dependence on medications, treatment side-effects, and knee replacement surgery. These concerns had generated significant worries and stress among the interviewees.

Expectations from treatment

In terms of expectations from treatment, patients generally expected an improvement in symptom control, prevention of deterioration of their condition, or even a cure. A small proportion (10%) indicated the wish to be better informed of their problems and the related treatments.

Discussion

Qualitative research is a powerful way of uncovering complex experiences among patients with OA of the knee.[18,19] The qualitative methodology used in our research has generated data to fill some gaps in the knowledge of management of the disease by providing information on how patients describe their symptoms, how the symptoms affect their quality of life, how they perceive the impact, what they expect about treatment, and their health-

seeking behavior. This knowledge may help doctors to become aware of and to understand the problem, needs, and expectations of patients with OA of the knee. Three interesting areas are identified in this research.

Discrepancy between self-evaluated disease severity and corresponding pain score

A previous study found that patients with moderate pain gave a self-reported VAS score of 4.9 and patients with severe pain gave a VAS score of 7.5.[20] In our study, 45% of patients (nine patients) gave a self-reported VAS pain score of between 4 and <8, which should be moderate to severe pain according to the definition from the previous study. However, a much higher percentage of 60% of patients self-graded their knee OA to be moderate to severe. Similarly, 10% of patients in our study (two patients) gave VAS pain scores from 8 to 10 signifying very severe pain, but 20% of patients self-graded themselves as having very severe knee OA. Although the number of patients in our study is too small to draw any conclusions, patients appeared to classify the severity of their OA at a higher grading than what they would have classified their knee pain. This indicates there may be other co-variables, such as impacts on physical, social, and psychological factors that patients would take into consideration when they self-evaluate the severity of their disease.

Two types of pain described by patients: mechanical and inflammatory pain

Of all the symptom descriptions given by patients during the interview, pain was by far the most discussed. According to the detailed description of pain in our study, two major types of pain were experienced by patients with OA of the knee, namely mechanical pain and inflammatory pain. The majority of the patients were able to distinguish between the two distinct pain patterns as their characteristics differed quite significantly. Healthcare providers should be aware of their presence and understand their different nature as the management of each could be different. For example, while non-pharmacological treatments like exercise, appliances (sticks, insoles, knee bracing), and weight reduction addressed the biomechanical issues of mechanical pain, patients in our study found that resting and ice packs were more useful in containing their inflammatory pain. While use of paracetamol as advised by international guidelines on management of OA of the knee[21-24] may be good enough for controlling the milder mechanical pain, NSAIDs might be needed to address the stronger pain from the inflammatory components of the disease.[25-28] On the research perspective, while the WOMAC5[29] and ICOAP knee version[30] provide quantitative measurements of pain in knee OA, the quality of the pain itself, whether it is mechanical or inflammatory, is not addressed by these tools. If these tools were used to measure the efficacy of pain control by medications or interventions, it may be difficult to segregate patients with inflammatory pain from those with mechanical pain in the cohort, as one of the confounding variables. This may be one of the reasons why previous researchers reported conflicting findings on whether paracetamol and NSAIDs were equally effective in the control of pain associated with OA of the knee,[31-33] given that if the cohort had more patients with inflammatory pain, NSAIDs would give better results.

The importance of communication in better management

Our study showed that there were great variations of symptoms among patients with OA of the knee and that it would be difficult to embrace all these symptoms just by filling in standardized questionnaires. Good communication and history taking is essential in order to understand the patient's perspective of the disease and its impact on physical, social, and psychological functioning. An example is that the prescription of a walking stick by a doctor was refused by a patient in this study. This patient took the walking stick as a sign of illness and stigma of disability although it is well accepted from a doctor's perspective that this is a standard non-pharmacological approach in knee OA management. Hence, it is essential to acknowledge patients' perceptions, doubts, and concerns during patient management, as they were identified in our study to be generators of patients' anxiety and worries.

Conclusions

The findings of our study suggest that there are two distinct patterns of pain described by patients, mechanical and inflammatory pain, each with distinct characteristics and onset patterns. Healthcare providers should understand and be aware of their presence as their management could be very different. The finding of discrepancy between self-evaluated disease severity and pain score suggests that there may be factors other than pain that patients consider during evaluation of severity of their disease. Thus, it may be beneficial if later research examines how patients evaluate pain and what parameters they prioritize during the severity evaluation. Finally, this study has demonstrated that knee OA patients can present with great variations of symptoms, have different disease perspectives, and show different health-seeking behaviors. Doctors need good communication with better understanding about their patients to clarify misunderstanding and alleviate patients' anxiety, which in turn will improve the treatment outcome of patients with OA of the knee.

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