

Narrative of Southeastern Mexican patients with osteoarthritis: A focus group interview study

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ABSTRACT

Introduction. Narrative Medicine serves to accompanying the patient through the experience of his/her illness, listening to his/her story in a simplified therapeutic role. The aim of this interview-based study was to explore in a group of patients with OA from *South-Eastern Mexico the content of their narratives regarding their illness.*

Methods. Eight patients with OA participated in five focus group interviews that were tape recorded and transcribed verbatim. The narrative was analyzed considering the number of mentions and theoretical saturation with three dimensions: pain, stiffness and functional capacity.

Results. Pain was associated with quality of life, religiosity and social interactions. Regarding stiffness and functional capacity, participants expressed the appraisal of illness as an inevitable deterioration and a rather passive coping response.

Conclusions. Narrative-based evidence on how patients with OA perceive and manage their illness underscore health as a concept where the physical and psychological dimensions are in an ongoing interaction; thus, calling for more sensitivity from the medical community and for a comprehensive interdisciplinary treatment.

Resumen

Introducción. La medicina narrativa sirve para acompañar al paciente a través de la experiencia de la enfermedad, escuchando su historia en un papel terapéutico simple. El objetivo de este estudio basado en entrevistas fue explorar en un grupo de pacientes con OA de Yucatán el contenido de las narraciones sobre su enfermedad.

Métodos. Ocho pacientes con OA participaron en cinco entrevistas de grupos focales que fueron grabadas y transcritas textualmente. El análisis narrativo consideró el número de menciones y la saturación teórica con tres dimensiones: dolor, rigidez y capacidad funcional.

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Resultados. El dolor se asoció con la calidad de vida, la religiosidad y las interacciones sociales. Con respecto a la rigidez y la capacidad funcional, los participantes expresaron la valoración de la enfermedad como un deterioro inevitable y una respuesta de afrontamiento bastante pasiva.

Conclusiones. La evidencia basada en la narrativa sobre cómo los pacientes con OA perciben y manejan su enfermedad subrayan la salud como un concepto donde las dimensiones físicas y psicológicas están en una interacción continua; por lo tanto, se requiere una mayor sensibilidad de la comunidad médica y un tratamiento interdisciplinario integral.

INTRODUCTION

Osteoarthritis (OA), also known as “wear and tear” arthritis or “degenerative arthritis”, is a debilitating and deforming disease characterized by the inflammation, breakdown and subsequent loss of cartilages in the joints. Although the term “osteoarthritis” is often used interchangeably with “osteoarthrosis” it must be noticed that OA implies inflammation of the joints (1). Its main symptoms are pain, morning stiffness and a tendency for the affected joint to gel with immobility. Knee, hip, hand, ankle, wrist and shoulder joints are the most commonly affected (2). Possible etiological factors include developmental, genetic, metabolic, and trauma related anomalies (3). Older age, female sex, genetic predisposition, overweight and obesity are some identified risk factors (4-5). OA has become one of the most common, costly and disabling forms of joint disease. For instance, the 2010 Global Burden of Disease Study reported hip and knee OA ranked as the 11th highest contributor to global disability and 38th highest in disability-adjusted life years (6). Adult OA prevalence is estimated in about 10.5% in Mexico (7), and in about 6.8 % in Yucatan, in South-Eastern Mexico (8).

Patients with OA must live with a chronic condition that often brings physical pain and limits autonomy. This condition might be emotionally challenging and patients find themselves in need of support to transcend the suffering caused by their illness. Medicine is called upon to relief suffering;

however, in a robust quest to cure disease and extend life, its attention seems to have fallen by the wayside. In some cases, medical treatments exclusively focused on the physical dimension of illness may ameliorate bodily symptoms; notwithstanding, at the cost of exacerbating emotional suffering (9). Within this framework, Narrative Medicine (or Narrative-Based Medicine) has developed as a theoretical and operative approach aiming at introducing into daily medical practice the use of narrative as a tool to collect and interpret information from the patient's point of view (10). Narrative Medicine serves to accompanying the patient through the experience of his/her illness, listening to his/her story in a simplified therapeutic role. People are essentially storytellers, and the content of the stories they tell and listen shape their attitude towards their lives. This becomes particularly relevant in patients who are suffering of painful and disabling chronic illnesses, such as OA.

The aim of this interview-based study was to explore in a group of patients with OA from South-Eastern Mexico the content of their narratives regarding their illness. Information would help sensitize health professionals about possible emotional issues that patients with OA might be facing and that they should consider in their clinical practice.

METHODS

The Research and Ethics committees of the School of Medicine of the Autonomous University of Yucatan approved the study protocol. The present study is part of a larger project about psychological well-being in patients with OA in South-Eastern Mexico (11).

Participants were recruited from a public secondary health care institution located in the city of Merida, South-Eastern Mexico. Eight participants (3 males, 5 females) were included, all meeting the following criteria: 1) a clinical and radiological diagnosis of OA confirmed by a physician specialized in physical medicine and rehabilitation, 2) OA in lower limb (knee and/or hip), 3) reported pain and stiffness in

joints, 4) limited functionality in OA location, 5) without other chronic illness, 6) aged 45 or older and, 7) non-compromised cognitive functioning. All participants were natives from South-Eastern Mexico and had a minimum of 9 years of education. Written informed consents were signed, with no economic compensation involved.

In addition, according to the theoretical criteria of saturation of the categories investigated, that is, until the additional data that was collected did not add significant information to what was already had, the total number of interviews of the participants was decided (12).

One of the authors (DE), a PhD psychologist and researcher, performed the five focus group interviews with selected participants. Interviews lasted between 60 and 90 minutes, they were tape recorded and transcribed verbatim. All authors together analyzed the narrative content of interviews considering the number of mentions and theoretical saturation with three dimensions: pain, stiffness and functional capacity.

RESULTS

The presentation of the results has been organized in 2 sections: the discourse on pain, rigidity and functional capacity obtained through the interviews and secondly, the categories and subcategories found are presented (Table 1).

The discourse on pain presented by patients with OA can be seen in the following sentences:

“I remember that it was pain so I need medical attention, after the studies, the doctor told me that I had OA. 6 years ago and the pain does not leave me, it comes and goes and sometimes it gets worse” (Ana, pain, 66 years).

“X-rays were necessary because my knees hurt a lot and pain did not go away, it hurt my arms and even my hip. I could not sleep at night. I

went back to see the doctor, and he explained me that I had degenerative OA and prescribed drugs” (Carlos, pain, 65 years).

Further, regarding stiffness, patients mentioned it is highly related to the things they still can or cannot do.

“For a long time it has been difficult for me to get used to the difficulty of moving. What I do, when I cannot move, is staying still and waiting” (María, 56 years).

Finally, it is important to mention that during the interviews the functional capacity was the most difficult belief to address, as the concept was not as clear to them as the other two.

“This disease, in addition to pain gives you a sense of uselessness. Not having (functional) capacity is a punishment, a curse” (Esperanza, 59 years).

The results show that in relation to pain was the most frequently addressed dimension with three particular themes explained as it follows. The patients associate it with a) quality of life related to health and physical pain. Patients reported concerns about how to prevent and manage physical pain as they see it as an important aspect affecting their quality of life; b) pain and religiosity. Religiosity was spontaneously mentioned as an important factor influencing how they interpret and face pain and c) Patients resent pain to limit their interaction with others within their social network (Table 1).

Table 1. Narratives of Patients with OA

| Narratives | Number of mentions |
|---|--------------------|
| Category: Pain | |
| Subcategory: Quality of life | |
| “My quality of life depends on my health that is why I visit the doctor when I am in pain and medicines don’t help” | 8 |
| “Medicines relieve pain” | 5 |
| “I must take my medicine, or else, my quality of life worsens” | 4 |
| “I apply heat to prevent the pain to increase” | 4 |
| “I avoid sudden heat and cold changes because pain increases and lasts longer” | 4 |
| “Going to rehabilitation takes the pain away and gives me quality of life” | 3 |
| “I have been kneaded to alleviate pain because sometimes not even medicine brings relief” | 3 |
| Subcategory: Religiosity | |
| “I ask the Virgin a lot to relief the pain” | 8 |
| “To improve my health, I pray to God a lot, He helps me to be lessen (the pain)” | 8 |
| “I pray to feel relief” | 8 |
| “I pray to my Saints to relief the pain” | 8 |
| “If pain is not much I can go to mass” | 5 |
| “I ask to God a lot to give me a better quality of life, free of pain” | 4 |
| “God takes away my pain” | 3 |
| Subcategory: Social network | |
| “I ask others to help me because pain does not let me do many of my activities” | 8 |
| “I ask my children to stay close when I cannot do my things because the pain does not let me (do them)” | 8 |
| “I feel rage because I cannot do my normal things because of the pain, especially when all my children cannot help me because they have to see their things and children” | 7 |
| “I ask my children a lot to help me when I cannot move to do my things” | 5 |
| “My children are on the watch and worry a lot in case I am in pain, because they have seen how I get when it hurts” | 5 |
| Category: Stiffness | |
| “What I do, when I cannot move, is staying still and waiting” | 8 |
| “There are good days and bad days because I cannot move, I stay more rigid” | 8 |
| “I try to move more otherwise it is worse, what helps me is that I have no pain” | 6 |
| “If I cannot move I stay like that and that is it, I cannot do anything” | 6 |
| “If the body does not respond, I take a rest” | 5 |
| “I ask God a lot that I can move” | 3 |
| Category: Functional capacity | |
| “It has to do with age, you do not have the same capacities and if besides you feel pain and you do not move enough you are limited and that is not quality of life” | 8 |
| “I do not move, I do not walk, I cannot do anything, it is not the same, the capacity runs out” | 7 |
| “My capacity has to do with deterioration due to age and the illnesses I have” | 7 |
| “You do not have the same capacity but there is God helping me” | 5 |
| “Feeling pain and not being able to move and being limited is like being dead” | 5 |
| “Not having (functional) capacity is a punishment, a curse” | 4 |

DISCUSSION

We report a qualitative analysis of patient narratives regarding their illness, OA. Through the selected themes of pain, stiffness and functional capacity, patients shared their views about symptoms and about how they daily overcome them.

OA pain is a common symptom with multifaceted etiologies within and outside the joint. As a complex phenomenon with a strong subjective component, pain perception is influenced by the nature of the underlying disease, personal predisposition (biological and psychological), and environmental and psychosocial factors (13-14).

Narratives underscore the impact that pain has in their perceived quality of life. These results are in line with previous studies reporting that quality of life in patients with OA depends mostly on the pain in the joints upon movement (15-16), even more than on joint stiffness (16). Various studies support that the presence and severity of neuropathic pain are associated with greater impairments in quality of life. However, as this impact varies somewhat as a function of the domain being considered (17), a finer analysis of quality of life domains must be considered in further studies.

Results from the present study support the relevance that spiritual beliefs have on the patients' ability to cope with OA pain. Some patients with pain use a number of cognitive and behavioral strategies to cope with their pain, including religious/spiritual factors, such as prayers, and seeking spiritual support to manage their pain (18). Nevertheless, it must be underlined that this approach is not effective for everyone. For instance, prayer was found to reduce pain intensity and pain unpleasantness but only for those who consider themselves religious (19). Although scientific research regarding the role of spirituality / religion as a core component in palliative care is relatively low (approximately 6.3%) (20), interest and recognition are growing, demanding further replications. In clinical practice, health professionals, regardless of their personal beliefs, particularly those attending chronic deteriorating illness, must consider the significant influence that the spiritual dimension might have

in some patients. By doing so with kindness and respect, they will help patients to cope better with their illnesses.

The social aspect was another significant topic related to OA pain. In the presence of intense physical pain patients are likely to withdraw from social interaction. Unfortunately, this may initiate a deteriorating circular interaction: pain prevents social interaction, and poor social interaction increases pain sensitivity. Depressive symptoms often occur as a comorbid condition in OA, probably due to the emotional impact of facing a chronic illness while at the same time seeing their social role becoming more restricted as pain increases. Although interaction with others may bring social strain, the social support received may not only reduce depressive symptoms but even buffer any negative effect of social demands (21). In patients with OA, less satisfaction with time spent in social roles due to illness has been associated with greater pain and illness intrusiveness, whereas less satisfaction with role performance was associated with greater illness intrusiveness and depression (22).

Stiffness is common in OA; joints may feel stiff after rest, for instance when waking up in the morning, but this usually wears off as the person gets moving. Participants seem to feel powerless when facing stiffness, deciding to passively rest and wait. Forcing movement is not recommended; in spite of that, inactiveness may in the long term increase pain and stiffness to the point where the individual is impeded to perform ordinary tasks at work or at home. Not to mention, he/she may feel ashamed of becoming dependent on others to do simple things such as standing up, walking, grasping and holding objects. This comes in line with their view on functional capacity; patients seem themselves incapable to do anything to face an inevitable pathway of deterioration, gradually losing mobility and quality of life. This posture is usual in OA patients, and even in medical staff. A review of narrative studies regarding OA, found that both patients and doctors believe OA is a normal part of ageing, it has an inevitable decline and there is little that can be done about it (23). In addition

to pharmacologic prescriptions, alternative low impact exercise should be considered. For instance, Tai Chi has shown some positive effects to relief stiffness on patient with OA (24-26), and also to reduce pain and improve physical function (24-27). Yoga therapy has also given some promising results, reducing pain and stiffness (28-29), state and trait anxiety, blood pressure and pulse rate (29), and improving physical function and psychosocial well-being (28). Mind-body practices, as tai chi and yoga, seem useful to alleviate pain and enhance physical function in OA patients; however, potential benefits and the underlying mechanisms still need to be tested systematically (30). Beyond physical symptom amelioration, it must also be underlined that exercise programs help improve psychological well-being, sense of self-efficacy and social function (31). Regarding stiffness and loss of functional capacity, patients in this study consider there is little they can do. Mind-body practices must be considered as adjuvant treatment; group sessions will give them the opportunity to interact with others and they can also be rehearsed at home, but most importantly, they can ameliorate their physical symptoms, improve daily functioning and also give them back a sense of control.

Narrative methods are of qualitative nature and this might bring into question the generalization of results. Nevertheless, it allows finer and deeper analysis on what patients have in mind and are willing to express. Furthermore, as data collection is person focused, it provides patients the opportunity to be listened and to feel their opinions are being considered, favoring physician-patient alliance.

To the best of our knowledge, this study provides for the first time narrative-based evidence on how patients with OA from Southeast Mexico perceive and manage their illness. This first approach serves not only to encourage further research on this topic but also to promote among the community of health professionals awareness on the relevance that patients' beliefs have on their overall quality of life. Narratives underscore health as a concept where the physical and psychological dimensions are in an ongoing interaction; thus, calling for more

sensitivity from the medical community and for a comprehensive interdisciplinary treatment.

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