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Reprint

Evaluation of the expectations osteoarthritis patients have concerning healthcare, and their implications for practitioners

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Abstract

Background

The expectations of patients with osteoarthritis are essential for health care provision and may be used to improve the patient-doctor relationship.

Methods

A total of 96 osteoarthritis patients aged 42-89 years (mean = 65; 81% female) were recruited among customers of 10 pharmacies in 10 towns in 10 regions (selected at random from the 22 French regions). Ten focus groups were organized looking at three categories of expectation: 1) Information about and understanding of osteoarthritis; its impact on lifestyle, and its treatment, consequences, and outlook; 2) Communication skills, attitudes of practitioners and communication between health professionals; 3) Support available from doctors, family circle and society.

Results

The patient-practitioner relationship begins with a dialogue, the quality of which, the participants could be improved by: developing greater trust: patients expect communication skills and expressions of sympathy that practitioners seem ill-prepared to provide. Strengthening involvement: general practitioners in particular should act as mediators and facilitators to improve recognition and understanding of osteoarthritis by employers and public decision-makers.

Conclusions

The present study enabled patients to express their expectations. Meeting those expectations could markedly improve the therapeutic process, but the question arises of whether practitioners are ready to agree that there is a need to reconsider and modify the care they provide for their patients.

Key words

Trust, implication, patient-practitioner relationship, focus groups, osteoarthritis, expectations.

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Introduction

As medicine moves into the twenty-first century, the emphasis in physician-patient relationships is increasingly on patient and doctor sharing responsibility for decision-making and treatment outcomes. This reflects both a growing desire among patients for participation in their care, and the increasing proportion of people with chronic diseases requiring long-term treatment and lifestyle intervention.

In 1956, a 'mutual participation model' of the relationship was described between the practitioner and the patient with a chronic disease (1). Under such circumstances, the patient's own experience is an essential component of the therapeutic approach, as he or she is responsible for much of its implementation. In essence, the practitioner helps the patient help him/herself.

In 1978, the concept of the 'negotiated order' between patient and practitioner was introduced (2), whereby the relationship is not predetermined, but established by negotiation and open to modification at any time - for example if the patient requires more information. The implication of the Szasz and Hollender, and Strauss models is that in non-emergency situations, patients do not necessarily interact passively with their doctors. They ask questions, seek explanations, and make judgements about the appropriateness of the information they are given and the treatment provided.

Osteoarthritis (OA) is the most widespread rheumatic disease in the world, and as populations age it can be expected to increase in prevalence, with many patients requiring health care for the rest of their lives (3). One aim of the worldwide partnership embodied in the Bone and Joint Decade, a multidisciplinary and collaborative initiative launched in 2000 by the World Health Organization, is to improve the health-related quality of life of people with musculoskeletal disorders (4). European reforms in medical law, particularly regarding consent and patient rights charters, have been made on that basis.

Patient satisfaction is increasingly recognized as a key aspect of policies

aimed at improving the quality of care in Europe, and in some contexts has become a social and economic priority. In 2004, the European Foundation for the Improvement of Living and Working Conditions (5) has issued a recommendation concerning the relevance of asking citizens directly for their views on the quality of the health service.

In order to elucidate the social and cultural components of patient satisfaction, many authors have investigated the degree of discrepancy between expectations and experience. These 'gap models' propose that satisfaction is achieved when experience is as good as, or better than, expected; dissatisfaction occurs when experience fails to live up to expectations (6). An alternative approach is to use the 'model of patients' expectation and requests (7) which focuses on the difference between the actual care provided and what patients were told beforehand (8).

If the aim of health systems is to adapt programs and facilities to the needs of patient communities, it is relevant to explore the expectations of those communities. This can be done using focus groups to gather qualitative and collective information about what constitutes satisfaction. Generally, focus groups provide an opportunity to review opinions and ideas that emerge when participants interact, and emphasize the importance of individuals as 'actors' within a group. In the present context, they allow for the exploration of patient expectations in all their complexity, and involve patients in determining how the quality of their care can be improved (9).

The personalities of practitioners, their attitudes and what they say, are known to influence satisfaction with care provision in OA; however, little is known about what patients actually expect from the patient-physician relationship (10) and whether these expectations are specific to OA. The aim of the present study was to evaluate the expectations of OA patients in France and to consider how the information gathered may be used to improve the health care provision and patient-doctor relationship they received.

Competing interests: none declared.

Methods

Sampling

The first 10 customers who came to purchase medication, of whatever nature, for their OA were recruited at 10 pharmacies in 10 towns* in 10 regions (selected at random from the 22 French regions). Pharmacists obtained written consent from volunteers.

Procedure

Ten focus groups with 10 participants were conducted by two teams of two interviewers using a semi-structured interview guide. The focus groups described here lasted for about 2 hours. In this study, the main topics selected were about:

1. Set up phase: each participant answers the following questions on a piece of paper:
 - What is osteoarthritis? What are your expectations with respect to osteoarthritis?
2. Then each person reads his/her answer to the rest of the group.
3. Next stage: activities about the main themes:
 - Presentation of osteoarthritis (15 minutes): what do you know about osteoarthritis?
 - Living with the illness (25 minutes): pain, mobility, sleep, weight, social relationships, professional life, everyday activities, morale, information received.
- Medical assistance (15 minutes): care, explanations, undesired effects, quality of the relationships with the contributors.
- Information (20 minutes): communicating with the Doctor, clarity of the explanations given, preoccupations of the changes with osteoarthritis, informing your next of kin.
- Expectations (15 minutes): foreseen improvements, ideals, new treatments.

cultural values and elucidates what participants have in common, allowing them to explore and clarify their views in a situation that permits the expression of criticism. Focus groups are particularly well suited to the study of attitudes and experiences, and can shed light on how opinions are reached within a given cultural context. Interaction between members of the group tends to produce insights that would not surface in individual interviews. Data are obtained rapidly, and specific themes, and new ideas (or ways of expressing old ideas) emerge (11, 12).

Each interviewee also completed a self-administered questionnaire covering socio-demographic characteristics (i.e. age, sex, education level, and way of living) and details of their OA (joints affected, degree of pain) and its treatment (medications).

Data analysis

Two teams of senior academic sociologists and rheumatologists conducted qualitative analyses of focus group transcripts (11). The information derived was classified into categories, the labeling of which was determined by consensus; items were then entered verbatim into the relevant category (13). The population was described in terms of sociodemographic variables.

Results

Of the 100 patients approached, 96 agreed to take part in the study (mean age, 65 years [range, 42-89]; 81% women). The average history of OA was 18 years, and 86% respondents were regularly taking medication to relieve pain. Joints affected were: knee, 66%; finger, 50%; hip, 46%. More than half (55%) were living in flats, 48% were living alone, 42% with a partner, and 10% with another family member. Educational levels were: 28% primary, 37% secondary, 26% *baccalauréat* or higher education, 9% non-response.

Categories in which the care offered by health professionals did come up to expectations were:

1. Information;
2. Communication skills;
3. Social support.

Each of those areas is considered below. A summary of the issues raised is followed by verbatim remarks identified during the analysis as reflecting the predominant attitudes of patients (13).

1. Expectations in terms of information: knowing as a way to better understanding

The main issues patients required more information about in order to cope better with daily life related to their disease, its origins, the outlook, and the role and possible side-effects of treatment. Information about recent developments was seen as inadequate. Without information, there was a tendency to think of the disease as a consequence of lifestyle - leading to guilt - or as bad luck. In order to cope with OA, patients said they needed information that would help them accept the diagnosis and the uncertainty and doubt about the future that goes with it. Knowledge helps patients develop a dialogue with practitioners and become partners in managing their OA. The ability of patients to communicate their daily experience to the practitioners is a priority if they are to build genuine agreement and if the best treatment strategy for each individual patient is to be identified.

OA patients surveyed appeared to feel that they had too little opportunity to express themselves. Practitioners, in turn, possessed knowledge that they could pass on to patients in order to promote self-reliance and the self-confidence required to cope with the anxieties inherent in all chronic diseases. Fear of impairment and handicap is pervasive in OA. Even so, patients felt able to enter into an association with the practitioner and to establish a therapeutic contract. They therefore would expect the practitioners to help them help themselves, which requires the time and opportunity for self-expression. Patients also wanted to be able to ask questions of their practitioners and to see them, above all, as genuine partners. These attitudes are close to those observed among cancer patients in an Australian study, who stated that lack of discussion made them unable to take part in decisions about treatment (14). Patients said they were surprised when

*Strasbourg (north-east), Paris (centre-north), Bourges (centre), Rennes (west), Amiens (north), Auxerre (centre), Mont de Marsan (south-west), Nice (south-east), Chambéry (south-east), Evreux north-west.

their GPs did not have specific information on new treatments or means of preventing OA in their children and grandchildren. The question of the efficiency of research was also of concern.

Specific comments included the following (13):

Causes and course of OA

'Are there young people with this disease?'

'I know elderly people who have nothing wrong!'

'It's bad luck'; 'You can't blame yourself for that' (response to a person who had engaged in a lot of sporting activities).

'Does work involving repetitive movements and being always in the same position cause the disease?'

'What causes it?'; 'Is it common?'

'Can it get worse again?'; 'Am I likely to go on to worse disability?'; 'Am I likely to become bedridden?'; 'I am afraid of being in a trolley'; '...in a little (wheel) chair'; '...especially when you are living alone'.

Daily life and prevention

'Do climates or food have an effect?'

'Is walking a good thing?'; 'Are there things you should or should not do – a lifestyle to be avoided?'; 'What predisposes (people to OA)?'

Treatment and its effects

'I would like someone to explain to me why and how the dose should be increased when there is a flare-up, and why it is decreased afterwards.'

'Why is it important to avoid getting too used to these drugs?'; 'Are there side-effects?'

Training and new developments

'I would have preferred (him) to have had training for this disease'; 'I'm sorry (he) does not have more time to get information and pass it on to me.'

'Are there any new developments - with lesser side effects?'; '(He) does not even know about it'; 'The ideal thing would be a drug that regenerates'; '... that rebuilds damaged cartilage.'

'Can you graft cartilage?'; 'Is there an efficient treatment other than operation?'

Outlook and research

'Is it inherited?'; 'Will our children and grandchildren get it too?'; 'Is there a way to prevent it in young people?'

'Is research progressing?'; 'Are there a lot of researchers working in this field?'; 'Do they have means available?'; 'Are there experimental centers?'

2. Expectations in terms of communication skills: improving dialogue

Issues in this area included finding better ways to talk to patients, giving explanations in suitable form, and facilitating transfer of knowledge and information. Patients wanted practitioners to participate in an authentic teaching process. The majority of the problems highlighted relate to vocabulary and teaching tools (lack of diagrams). There is a need for more clarity, accessibility, and simplicity.

Computers may facilitate information management, but do nothing to improve communication because they 'steal' time from relationships, and may upset the patient by 'hiding' the practitioner's face. Facial expression and body language enhance communication. Patients said practitioners were often not explicit enough when discussing the seriousness of the diagnosis or the value of certain drugs compared with others. They were frequently seen as being distant, with little time to listen, understand or explain, and were often perceived as tactless. Inappropriate gestures generate anxiety; for example, a shrug is no substitute for a clear answer. Some lack of dialogue seems linked with avoidance strategies, such as minimizing suffering, using fatalistic wordings, and being difficult to approach.

Lack of communication skills is crucial in some exchanges, notably regarding pain. Silence from the practitioner was interpreted as powerlessness, and patients stopped asking questions. Yet they would be prepared to hear the practitioner say 'I don't know', and to be sent for a second opinion. Advice and response to questions, in particular about topics highlighted in the media, were seen as generally good, but patients often felt that they had to seek

information rather than being given it spontaneously.

Patients referred to other practitioners by sealed letter felt left out. They wondered about the relevance of such referrals, and the real benefits for themselves and their disease management. A study conducted in UK on the perception of medical care among patients with a chronic fatigue syndrome showed similar concerns (15). Dissatisfied patients complained about poor quality treatment and late diagnosis, and described practitioners as fatalistic and poorly informed about the disease. Satisfied patients appreciated their practitioners because they gave them time and support, and took an interest in their disease.

Specific comments included the following:

Language used by practitioners

'Words that everyone understands';

'My doctor explains things very well, she shows me, does drawings.'

'I ask questions and so does he.'; 'We try to work together'; 'I am the one who manages my pain and my condition according to need.'

Computers

'His face is hidden by the computer.';

'His eyes are on the computer, I can't see the way he is looking.'; 'The consultations could almost be done over the phone.'

Attitudes of practitioners

'They don't understand us, they don't listen to us.'; 'They are very cool.'; 'They are tense.'; 'They don't take enough time.'

'You have to get them to talk, I'm afraid if you don't ask, they don't say anything.'; 'They tend to avoid the question.'; 'They don't want to say too much.'; 'Take this and that, with no explanations.'

'They have no cure.'; 'They are helpless'; 'You just have to put up with it and that's that.'

'You dare not ask (for information).'; 'They don't really like people asking questions.'; 'He made me feel I was being a nuisance.'; 'I told him about newspaper articles about a new treatment, and he just waved it away.'

Gleaning information

'You always have to take the initiative.'; '(I have to say) I am suffering terribly, please give me something.'; 'You always have to ask.'

'A doctor can't know everything.'; 'I feel that (the doctor) was right and courageous when he said that he couldn't give me clear information, and he sent me to someone who could.'

Exchange of information between practitioners

'Even if they do communicate, what does that do for us and our illness?'; 'I don't get the impression that there is any real discussion between them, they just pass on information.'; 'You are just an object, a ping-pong ball going to and fro.'; 'They pass on x-rays and little notes to colleague that are sealed and you aren't shown what is in them.'; 'They should leave the letters unsealed.'; 'I feel I can open the notes.'; 'I try to understand what they are telling each other, it concerns me and I feel I have the right to know.'

3. Expectations in terms of support: recognition as a way to better involvement

Patients did not see much sign of interest in their disorder among practitioners, whereas they experienced its growing impact day-to-day (having to give up what they used to enjoy, having to stop caring about appearance, feeling that people are looking at them). In the medium term, physical limitations and emotional distress made life hard, and made it difficult to plan. As self-reliance is gradually eroded, and dependency sets in, the support provided by practitioners was considered an integral part of care provision. Much more understanding and support was also expected from the patient's immediate circle (at home and at work), particularly when friends and family did not see OA as a real disease. It was reassuring to be able to talk with other people who have the same illness. The importance of family support has also been emphasized among adults with type II diabetes (16).

Patients saw their GP as being the person to talk to day-to-day, and looked

to him or her to facilitate social recognition, act as a mediator with their close circle, and help them to explain their disease and the difficulties they encounter. They also expected the GP to have a regulatory role with regard to employers and medical authorities. Nevertheless, patients said they trusted their GPs and did not plan to change (as they may under the French system).

Patients did not understand why they are not given assistance, such as home helps. Official recognition of OA as disability would give it legitimacy in the eyes of the community, and the patient's immediate circle, lack of which was seen as an injustice. Likewise, the minimal coverage of OA in the media compared with other chronic conditions such as diabetes and asthma was considered unacceptable. Patients also all doubted the existence of research programs devoted to OA.

Specific comments included the following:

Moral support by practitioners

'All he does is to try to reduce the pain.'; 'You have to manage on your own.'; 'All I got was "you have to put up with it", while I am in pain every day.'

Advocacy

'Credibility'; 'The family should know'; 'He should explain, perhaps they (employers, health department...) would understand our problems.'

Trust in the GP

'The most important doctor is the one who knows you best - the family doctor.'; 'It all needs to be based on being able to trust him or her.'; 'Trust has a lot to do with cure.'; 'If he were really a bad doctor, you would change to another.'; 'If I didn't trust him I would go to another.'

Support from others with the same condition, and from people at home and at work; social recognition

'It's nice to feel that you are not the only one suffering.'; 'People who have the same disease as you always understand.'

'As you can't see it, people (family, friends) don't really sympathize.'; 'It

frightens people (at work), they don't want you to say you are not well.'

'It gives you pain, but you don't die of it.'; 'When it started, I was working, but people couldn't see when I had a flare so they thought I was making a fuss.'

Unrecognized disability

'Why is this disease not recognized, when it leads to disability?'; 'I was sent to the disability commission, but they did not recognize my condition, my disease.'; 'Even occupational medicine departments do not recognize arthritic conditions.'; 'You can't apply for state assistance because OA isn't recognized as a real disease.'

Research on OA, comparison with other disorders

'Do research labs really do proper research on this disease?'

'What you hear a lot about is diabetes.';

'You get the impression that in spite of all the research, OA is left out'; '...yet commercially, it brings in a lot for doctors, chemists and labs.'

Discussion

This qualitative research study investigated the OA patient-practitioner relationship. Participants suggested that the quality of the dialogue initiating and determining this relationship can be improved by *developing greater trust*: patients expect communication skills and expressions of sympathy that practitioners seem ill-prepared to provide; and *strengthening involvement*: general practitioners in particular should act as mediators and facilitators to improve recognition and understanding of osteoarthritis by employers and public decision-makers.

The study has some limitations. The study population comprised OA patients taking part in focus groups. They were not representative of French health system users overall. The method used entails limitations relating to recruitment on a voluntary basis, to data collection via focus groups, and to the subjectivity of individuals performing the qualitative analyses.

The findings of the study open some perspectives and suggest some area for improving practices. The use of focus

groups in the present study enabled patients to express their expectations. Meeting those expectations could markedly improve the therapeutic process, but the question arises of whether practitioners are ready to agree that there is a need to reconsider and modify the care they provide for their patients. The models of mutual sharing (1) and negotiation (2) quoted in the introduction make it possible today to make a better assessment of the ground covered, and of what remains still to be done if the relationship between patient and practitioner is to be a genuinely open one in which each party has a real influence on the other. The patient partner programme in which rheumatoid arthritis patients teach medical students about their condition could serve as an example of such sharing and patient empowerment (17).

Patient satisfaction with care provision depends not only on the knowledge of practitioners, but also (and to a greater extent) on their ability to make use of that knowledge and provide explanations, and on the quality of interpersonal relationships they establish. Practical relationships are ethically and legally obliged to pass on information and legally obliged to dialogue with their patients. However, the education they provide appears to be relatively neglected due to lack of skills, shortage of time, and poor recognition of its importance. This could be improved probably at the expense of the quality of content in setting this dialogue, rather than of increase in quantity of time of the visit, due to time constraints in the daily rheumatologist's practice. The first contact however should be sufficiently invested to establish such relationship decently, and therefore help filling the gap between true knowledge patients have to acquire about their disease and shortcomings and representations conveyed in society outside health care. Specific

identification (and possibly funding) of such visit could be proposed, according to health care system.

Knowing as a way to better understanding, and communication skills as a way to better dialogue, are important aspects of caring for patients with OA. The present results are in accord with the findings of a recent Dutch study (18) in which participants were on the whole very satisfied with the rheumatology care provided. Factors contributing to their satisfaction included 'being approached as a person', 'being treated respectfully', and 'being given enough room to mention all complaints'. Most critical comments regarding communication and behavior concerned small things open to change. The study concluded that physicians may not be aware of the impact of their behavior on patients.

The most likely model of interaction in future medical encounters is that of mutual participation - with the doctor and patient working together as a team rather than the patient simply following the doctor's orders more or less automatically. This approach can be seen as a prerequisite for the establishment of a genuine therapeutic process in which the practitioner can become a 'therapeutic educator' (19). Qualitative studies in other European countries would help identify those patient expectations of the highest priority in improving the provision of care in OA.

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