

Developing written information on osteoarthritis for patients: facilitating user involvement by exposure to qualitative research

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Abstract

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Introduction In developing a guidebook on osteoarthritis (OA), we collaborated with people who have chronic joint pain (users). But to advise, users need to be aware of and sensitive about their own state of knowledge and educationalists argue that adults sometimes lack such awareness. This paper will report on our experience of providing users with findings from qualitative research to increase awareness of their level of knowledge.

Method A summary of the results from qualitative research into people's experiences of living with chronic pain was sent to individual members of two groups of users. It was then used to structure group meetings held to help identify information needed for the guidebook.

Findings Some users found the summary difficult to read and suggested how to simplify it. Nevertheless, it helped most users to become aware of the experiences and views of others who have OA and thus become more sensitive to their own level of knowledge. It also helped them recall experiences that stimulated practical suggestions for managing joint pain in everyday life and provided a way of gently challenging the views of users when they appeared to assume that their views were widely held. The discussions brought to light gaps in the research literature.

Conclusion We believe this way of involving users by exposing them to qualitative research findings about lay experiences of living with OA effectively facilitated the users' contributions to the needs of those who have to live with OA, and we believe it has wider applications.

Introduction

At the Arthritis Research UK Primary Care Centre, written information for patients who have osteoarthritis (OA) has been developed

recently. The impetus for this has arisen from setting up a trial to evaluate the effectiveness of an intervention to implement the recommendations from the National Institute for Health and Clinical Excellence (NICE) on the care and

management of OA in adults.¹ In the implementation trial, the intervention consists of 'model' consultations between patient and the following: GP; practice nurse; and members of the wider primary care team. The NICE guideline recommends that health-care professionals should offer accurate verbal and written information to all people with OA to enhance understanding of the condition and its management. NICE do not specify the particular form that the written information should take. Because NICE emphasizes the importance of health-care professionals supporting patients' self-management, the Whole systems Informing Self-management Engagement (WISE) approach to care, developed at the National Primary Care Centre for Research and Development (NPCRDC), underpins the 'model' consultations.² The WISE approach makes recommendations about the format of written information to help support patients' self-management.

WISE is designed to connect with patient self-management practice at three levels: to improve patient information by tapping into existing lay expertise of living with a chronic condition; to train health-care professionals in ways which will provide patient-centred guidance; and to render the organization of services more responsive to patients' needs. The first level involves developing written information which includes both lay experiential and biomedical evidence-based knowledge, so that the information is not only about the disease but also about the illness (the impact of the condition on the patient).³ The NPCRDC refers to the written information as a guidebook, which is intended for use within the consultation, to help foster a collaborative approach between professional and patient.³

While making an appraisal of existing, commonly used leaflets on OA, only one was found to include patient experiences. But even here, the use of lay knowledge was minimal and not well embedded in the biomedical information.⁴ We therefore decided to develop a guidebook on OA compatible with the WISE approach. The NPCRDC, who developed WISE, has written a

paper on the research undertaken to develop a guidebook on chronic bowel disorders.³ We followed a similar process, including the involvement of people who have experience of the condition to which the written information relates.

Using lay expertise

The case for using lay expertise is a strong one, especially as written information for patients has been criticized for addressing what is seen to be important by health-care professionals rather than by patients.^{5,6} Lay people and health-care professionals may have different ideas about the role and value of written information.⁶⁻⁸ So it is seen to be good practice to involve lay people who have the relevant medical condition or experience of it, when developing written materials.^{9,10} Tapping into their knowledge also helps ensure that the information needs of patients are met.¹¹

Two advisory groups of people with experience of musculoskeletal problems helped develop the OA guidebook. However, unlike the NPCRDC chronic bowel disorders guidebook, the development of the OA guidebook was not a research project. The relationship between the person from our Centre who led its development and the members of the advisory groups was one of collaboration and partnership.¹² The lay advisors helped decide what should go into the guidebook by identifying the kinds of things that people who have chronic joint pain would want/need to know, but their personal experiences were not incorporated directly, as neither quotes nor examples. (The term 'lay advisor' as used here refers to the members of the advisory groups, and the term 'user' is employed when discussing generic issues surrounding user involvement.)

A number of issues have been raised in the literature concerning user involvement, including whether an individual's views can be representative.¹³ Users' expertise is seen to stem from their experiences; they have experiential knowledge, and this raises the question of how representative are their experiences. But in addition to

experiential knowledge, they are also likely to have acquired professional biomedical knowledge from various sources.¹⁴ Blaxter defines lay beliefs about health and illness as ‘commonsense understandings and personal experience, imbued with professional rationalizations’ (Ref. 14, page 46). As the nature of users ‘professional rationalizations’ will vary from individual to individual depending, for example, on what they have been told or have read over the years, and as user involvement itself can add to users’ knowledge about their condition, as is reported by Caron-Flinterman *et al.*¹⁵, it is inevitable that what users ‘know’ about a health condition, such as OA, will vary from one user to another.

Atherton¹⁶ has argued that there are two aspects to knowing about something. Firstly, there is the self-awareness of knowledge. Is the person aware of what he or she does and does not know on a topic? Secondly, there is the knowledge itself, in this case, knowledge about what information is needed by people who have OA. Both aspects range from no self-awareness/knowledge of information needs to complete self-awareness/knowledge of information needs and yet, despite the continuum, this can be depicted in a two-by-two table representing four states.¹⁶ (See Table 1)

Arguably, the ability to advise effectively on the information needs of a group of people, such as those newly diagnosed with OA, will depend on the advisors themselves being aware of what they do know (conscious competence) and do not know (conscious incompetence). But Table 1 suggests that there are two further possibilities for knowing, namely those who think they know but do not and those who are knowledgeable but are not aware of what it is that they do know. Atherton¹⁶ argues that it is the interaction between ‘knowing’ and ‘not

knowing that you know’, which is both a complex and a neglected area from an educational perspective. He makes a further distinction between those who do not realize what it is they know and those who realize they know but are not able to articulate their knowledge. He names the last the ‘problematic expert’.

People who have a long-term condition have a valuable role to play in helping make health services patient-centred because of the experiences they have gained through having that condition. Some of this knowledge is likely to be tacit and intuitive or common sense.¹⁴ It is likely that those who have a chronic condition will be unaware of how much they know. This raises a difficulty when it comes to using them as advisors for making services patient-centred, especially when involved in identifying information needs. They need to be moved from being ‘unconscious competent’ to becoming ‘conscious competent’.¹⁶

Qualitative studies provide another source of knowledge about patient experience. In the case of OA, there is a body of qualitative research, carried out in several countries, which has arisen from exploring questions ranging from how people cope with joint pain to what are their perceptions of OA, or exercise, or taking medicines and what use they make of health-care services. Exposing each member of each advisory group to this literature potentially provides a way of developing the advisors’ understanding, whichever state of Atherton’s model they are in. They have the opportunity to become aware of gaps in their personal knowledge and experience, discover unconscious errors and make taken-for-granted knowledge available. Taylor¹⁷ refers to this as reflective competence – literally, reflecting on one’s competence.

Table 1 Four states of ‘knowing’

	Have knowledge about a topic	Lack knowledge about a topic
Without self-awareness of level of knowledge	Not realizing that you know (unconscious competence and the problematic expert)	Not realizing that you do not know (unconscious incompetence)
With self-awareness of level of knowledge	Realizing that you know (conscious competence)	Realizing that you do not know (conscious incompetence)

The following is a report on our experience of exposing lay advisors to the qualitative research literature on living with, and/or receiving care for, chronic joint pain in later life, in order to increase their awareness of their own state of knowledge when assisting in the development of patient information materials on OA. This paper is not concerned with how to do a narrative synthesis of qualitative papers nor with assessing the value of including experiential knowledge in written information for patients.

Method

The lead author is familiar with the qualitative research literature on older people's experience of chronic musculoskeletal pain and had a list of 20 relevant research papers. A colleague, who was reviewing the literature on qualitative studies into how people manage chronic joint pain, cross-checked the list to ensure there were no obvious omissions. Eighteen papers were from qualitative studies, another was a report from a national arthritis support group and the other was a quantitative study of use of complementary therapies. The findings were summarized, by means of a narrative, across four themes: living with OA, managing symptoms, treatment (medicines, complementary therapies and surgery) and exercise/physical activity. Some of the quotations reported in the papers were included in the summary to highlight the points being made in each theme. Also included was a brief description of the method used to carry out the summary and a table listing the research papers reviewed, along with some of their key characteristics.

There were two groups of lay advisors. One group was made up of six members (five women and one man) from a local arthritis support group, and the other was made up of five members (two women and three men) from the Research User Group (RUG) at the ARUK Primary Care Centre. RUG is composed of lay people who have chronic, painful, musculoskeletal conditions and to whom the Centre's research proposals and on-going research projects are systematically referred for scrutiny, discussion and comment. The second author is a

member of RUG. The local group was set up to support people who have various types of arthritis, not just OA. One member of the group acted as gatekeeper and extended invitations to members who she knew had OA. The lay advisors were aged between 45 and 80 and had experienced chronic joint pain over several years. All had English as their first language. They were reimbursed according to rates recommended by INVOLVE (a national advisory group that supports public involvement in health research and the NHS). The lead author facilitated the groups, who met on three occasions in 2007. RUG members met in the ARUK Centre, and the local support group at the home of the lead author. The summary was sent out to each member of the two advisory groups at least a fortnight before each group met for the first time. The summary can be accessed at: http://www.keele.ac.uk/research/pchs/pcmrc/Grime/Lay_perspectives_on_OA.pdf

The summary was used to structure the first meeting of each group. Taking each theme in the summary in turn, each group was reminded of the key findings and then asked to consider the following:

1. Do the findings seem credible? Do they resonate with your own experience?
2. What information needs do the findings suggest that the participants in the research studies had? (Even if you have not shared the experiences as reported, what do they say to you about what should be included in the OA guidebook?)
3. Are there other information needs not included in this theme of the summary?

Finally, after completing their deliberations on each theme, members were asked if there were additional issues that had not emerged from this process.

At two subsequent meetings, the lay advisors reviewed draft content for the guidebook. On these occasions, there were incidental references to the summary, but it was not formally a part of the deliberations.

All three meetings were taped, and the first was fully transcribed. The lead author also wrote

up detailed notes shortly after each meeting. (The primary purpose for recording the meetings was to act as an aide memoire when developing material for the guidebook.) The transcript and notes were scrutinized, and three broad themes identified.

1. The lay advisors' experience of reading the summary;
2. The lay advisors' responses to the findings that were reported in the summary;
3. The ways that the facilitator used the summary.

Coding of the lay advisors' responses was refined and organized into subthemes.

Findings

The three broad themes that were identified will be used to structure the findings. The second theme, lay advisors' responses to the summary, was broken in to four subthemes, i.e. confirmation of existing views, making connections with the findings, gaps in personal knowledge and gaps in research knowledge.

Lay advisor experiences of reading the summary

It was clear at the first meeting that not all members had read (all of) the summary and that some had found it difficult to read.

I found that it was like reading a book with a writer that you don't know. You struggle a bit at first to try and get the hang of what they're getting into, and then you get the hang of it. ——— I had to read a couple of pages a few times, just to begin to sort of think 'What am I supposed to be getting out of it? What am I doing here?' Then it suddenly clicked, and I thought, 'That's it', and, 'I'm with it now'. And I think as we go on and do other things as well we'll get the hang of how you people (researchers) do write these things. It's a matter of style isn't it?

Members suggested ways the summary could be improved. The main one was that they were prepared to take the research method at face value, so from their point of view, a detailed section on the research methods adopted in the

various studies was not needed, and the report could start with the findings.

Lay advisors responses to the findings in the summary

Confirmation of existing views

There was a tendency, at least initially, for individual members to focus on aspects of the summary that were salient to them. So, for example, one member picked out complementary therapies as a major feature of the summary, although, in fact, there was relatively little on this topic.

I could relate to a lot of those things that were said in the paperwork (*research summary*), and it was very interesting to see that a lot of the things concerned alternative medicine, and a lot of people seem to be for the alternative side.

It turned out that she had found alternative medicine to be more effective than orthodox medicine.

One of the members of the group made up of people from an arthritis support group said that she had heard many of the things reported in the summary from people who attended the support group.

The comments tweaked memories of what people at the (support) group had said, in all their various forms. So, it wasn't new information as far as I was concerned. I had heard it, and the same excuses, before.

There was nothing in the summary to suggest that the authors of the research papers considered that their respondents were making excuses for any aspect of their behaviour. So it appeared that when she used the word 'excuses', she was interpreting the meaning of quotations in the summary from pre-existing conceptions about the motivation and reasoning of people who have OA.

Making connections with the findings

Several members said that the findings resonated with their own experience of living with arthritis. For example, one lay advisor picked up on people who have OA fearing they will lose their independence.

'Where is it? (*He can be heard shuffling through the summary*).

One, two, third paragraph down, about losing control. I have a wife who will take over, she'll make me do things, I can lose control. So, I can understand where people are coming from saying that'.

Another advisor took up the point about those who have OA risking losing their autonomy as a result of the way other people respond to them.

'Very understandable. Some people, how they respond, will turn you, more or less, into an invalid. We might have a difficulty but we're not invalids'. (*The rest of the group murmured agreement*).

Members of both advisory groups used stories to make points. One of these, which stemmed from the group discussing the findings in the summary about the use of distraction to draw attention away from pain, led to the idea of including a section in the guidebook on local opportunities for getting out and meeting other people, while at the same time doing something enjoyable.

The section on exercise in the summary caused one advisor to consider the use of terminology and its perceived meaning.

It's how you put 'exercise'. It might frighten some people off by thinking, 'Does that mean that I've got to go to the gym'. – In some people it might just be the case of standing up every 10 min or walking round the house. You know, something as simple as that.

The desired balance between the more theoretical aspects of biomedical information, such as the biology of joints and 'exercise', and more practical information about ways of alleviating joint pain and stiffness was considered. There was a clear preference for giving more attention in the guidebook for what those diagnosed with OA might do, rather than being given a lot of medical detail about OA itself – not so much about OA, but more on what to do when you have it. The importance of seeking professional help was readily acknowledged by the majority of users as was the importance of having a good relationship with a doctor. However, the main focus of the discussions in both groups was on what people

can do for themselves. This concurred with a finding in the summary where self-care was also commonly reported to be a preferred option.

The research findings on the use of mobility aids led one lay advisor to reflect on her recent holiday in Spain. There, she had observed people 'zooming around' using a type of stick, which was like a mountaineer's walking pole with a strap around the wrist which you grasped and which also had a spring in the tip. In winter, the tip could be replaced with a spike to grip in icy conditions. She thought that the pole would be more acceptable to men as it did not look like a walking stick and could be helpful to women when shopping because, unlike the conventional walking stick, it did not need to be propped up, with the inherent risk of falling when paying at the supermarket checkout, for example.

Gaps in personal knowledge

The summary appeared to stimulate many questions and ideas. The lead author noted at the time that:

The members used the review very effectively to consider their own experiences in the light of wider findings, and to identify the important things to cover in the guidebook. (*ARUK Primary Care Centre Research User Group meeting notes*)

However, some of the views reported in the research summary were in opposition to those held by some members of the groups, including views about the effectiveness of glucosamine and whether people who have OA might feel self-conscious because of the way they walk. In the case of the last example, in one of the advisory groups, all but one member felt it unlikely that people did feel self-conscious. The dissenting member said that when he caught sight of his reflection in a shop window he realized that he walked in an odd way, and he did feel self-conscious. His disclosure led to a shift in the opinions of the group on this matter.

Gaps in research knowledge

Discussions about what it means to grow old, and feelings about ageing, arose when considering that part of the research summary, which

reported that people were reluctant to use walking sticks because it made them feel old.^{18,19} This led to a realization that there was very little in the research summary about the emotional impact of a chronic condition such as OA. Members suggested that a whole section on feelings was needed in the guidebook and that should include material that might help encourage positive feelings.

Some members from one of the user groups decided to do some 'qualitative research' of their own. The support group to which they belonged organizes a regular hydrotherapy session at the local hospital. But, noticing that there was not much in the summary on the benefits of exercise through hydrotherapy, they interviewed some of the support group members who were using the hydrotherapy pool. Quotations from these interviews were included in the OA guidebook.

Ways in which the facilitator used the summary

Initially, it was difficult to get the advisory group that was made up of members from an arthritis support group, to move on from relating their experiences of having OA to using those experiences to think about information needs. This might seem surprising at first sight given that, for some time, they had been meeting each other most months in the support group. But the structure of these meetings – each one an organized event followed by a buffet – gave them little opportunity to share personal experiences in small groups and in a quiet setting. Meeting as an advisory group presented them with a rare chance to talk about their own OA experiences gained over the years. The research summary was a useful, though not entirely successful, vehicle for getting the discussion back on track and as a focus for questioning whether a particular experience was commonplace.

Sometimes, quite naturally, there were differences of opinion. For example, some were in favour of using complementary therapies, while others were not. Occasionally, a member would disagree not with a research finding but with the specific view of a participant as reported in a research study. In one instance, this arose in

relation to the use of painkillers for OA. The research studies found that reluctance to the use of painkillers was widespread.^{20–25} One lay advisor was frustrated that people would not use them.

(Member) feels many people are resisting medicines unnecessarily for fear of side effects when they are unlikely to do much harm and the good will outweigh the harm. (*Taken from lead author's notes of a group meeting*).

He wanted to include a clear statement in the guidebook to the effect that simple analgesics, such as paracetamol, do no harm, and that people with chronic joint pain should be sensible and dose with them on a regular basis. The facilitator used the summary to make the distinction between individual orientations towards the use of medicines or a group of medicines, such as painkillers, and individual knowledge about a specific medicine, such as paracetamol. This led the group to consider the intended reader of the guidebook and how to write it in such a way that did not assume that the reader subscribed to any particular point of view.

Discussion

Although the lay advisors showed they had comprehended and used the summary of qualitative research papers, which reported on published studies of people's experience of living with chronic musculoskeletal pain, it cannot be assumed that everyone will read (and understand) a summary prior to the first meeting of a user group. Some lay advisors did not find it easy to read. Summarizing each of its themes at the start of the first meeting helped ensure that every group member was aware of what was contained in the summary. The summary brought into the open a broader range of views and experiences of people with chronic musculoskeletal pain than could be expected from just the members of the two advisory groups and, in effect, put these on the agenda for the first meeting.

It is not possible to say precisely what difference the summary made to what emerged from

group discussions about what to include in the guidebook. However, it appeared to stimulate thinking and memories that might not otherwise have come to mind. For example, the advisor who reflected on the use of walking poles in Spain did so in response to that part of the summary, which concerned the reluctance of people to use walking sticks because it made them feel old. She then related her Spanish experience to a practical problem of using a walking stick when shopping. In Atherton's¹⁶ words, she moved from unconscious competence to conscious competence. Certainly, the fact that some advisors sought the views of people using the hydrotherapy pool about its perceived benefit was in direct response to the research summary. Although it might be disputed that what they did was good research,²⁶ their motive was clear. It was to give their belief the status of knowledge and that could be described as moving from conscious incompetence to conscious competence.

The person who facilitated the group discussions was able to use the summary to question how common some of the views and experiences of individual members were, and when an advisor was apparently focusing only on findings which concurred with his or her personal view to point out competing findings. On such occasions, the summary was useful for drawing attention to the possibility of unconscious incompetence. Working through the summary was a non-confrontational way of questioning advisors when they were proposing, for example, that the guidebook should contain advice based on personal experience which, according to the research literature, was not widely shared. It was also helpful when trying to get an advisor to distinguish between deciding on content for the guidebook based on his or her private opinion, for example, the need to persuade people to take medicines, and content based on a common view or experience that emerged from the summary, for example, the need to give information in a way that recognizes people often do not like taking medicines long term. Similarly, in the case of the advisor whose use of the word 'excuses' suggested that she saw some people's explana-

tion for OA as indicative of a lack of moral fortitude, the summary allowed her view to be explored in terms of less partisan findings from qualitative research. In turn, this gave another member of the advisory group the opening to say, 'Well, actually, that happened to me' or 'I felt like that', rather than being put in a position of having to directly contradict the person making the assertion.

Strengths and weaknesses of the method

Strength of the method was that the summary made available to individual advisors the views and experiences of a large number of people who had the same long-term condition. These individuals were also able to see to what extent their own experiential knowledge coincided with, or extended beyond, current qualitative research findings. As a consequence, they were able to point to gaps in the research literature. The summary also helped keep the meetings purposeful when discussion drifted away from the agenda.

Not every health topic has a body of research concerning lay views and experiences, so this method is not suitable for every topic. Moreover, only one of the various types of media was used to present the research findings, namely, a written summary. One advisor admitted that he had initially found the summary challenging to read. Others might have had a similar experience but did not speak up. A range of media may be more appropriate for some people. Further related work could throw light on this topic.

Conclusion

We found, when collaborating with users to write patient-centred information materials on OA, that it was beneficial to expose them to qualitative research findings which explore lay experiences of living with the condition. It is not necessarily a simple matter to access lay experiential knowledge and expertise. But by reflecting on the findings from qualitative studies, those lay advisors, who thought they knew but found they did not, had the opportunity to learn.

Those advisors who were knowledgeable but unaware of their knowledge could be helped to become aware of the tacit implicit knowledge that they had and, therefore, were helped to become more able to articulate it to the benefit of the contribution they then were able to make to the OA guidebook.

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