

Involving users in low back pain research

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Abstract

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Objective To involve users in the design of a research project that aims at describing a 12-month course of low back pain in an adult population sample (epidemiological strand), and to determine how patient and professional perceptions of low back pain and its treatment relate to the use of health-care and to subsequent outcome (qualitative strand).

Design Three focus groups were organized in the preparatory phase of the project with general practitioners, other health professionals and low back pain sufferers. Issues pertaining to the experience of living with, or treating low back pain were explored and users were asked to identify relevant research questions for consideration within the study.

Findings The focus groups revealed tensions between involving users as co-researchers for design issues and their role as sufferers and health professionals who want to share their narrative accounts of low back pain. The group discussions produced a wealth of material for analysis, but no explicitly stated research topics. Three key themes and the process of user involvement in the focus groups are discussed.

Conclusions The focus group format could be restrictive in that it allows for detailed exchange between participants, but is insufficiently geared towards the production of a research agenda. We draw conclusions as to possible approaches for user involvement in health services research design.

Introduction

In recent years, low back pain research has proliferated in many developed countries. Much attention has been paid to its impact on the population of working age, the increasing cost to the employer and health services and its cost in economic terms.¹⁻³ Explanations for the emergence of this apparent epidemic of low back pain have differed, but it has been argued that relying

solely on a medical model is insufficient.⁴ Such a multidimensional view of low back pain is evident in the body of work that has concerned itself with the experience of living with low back pain, or compared lay perspectives with the way in which health-care professionals diagnose and treat the problem.⁵⁻⁸ The last decade has seen an increasing number of both research-based and methodological articles^{9,10} that have legitimized the study of lay interpretations of health and

illness. The use of patients' perspectives has also gained significance within policy.^{11–13} Thus, a shift towards understanding the experience of low back pain and its treatment would appear appropriate and, in particular, an exploration of the relevance of this type of research for improving the quality of care.

This paper reports on the early stages of a research project that aims at describing the low back pain experienced in an adult population sample over a 12-month period, and to determine how patient and professional perceptions of low back pain and its treatment relate to the use of health-care and to subsequent outcome. An epidemiological questionnaire focuses on the course of pain and disability in the study sample, and qualitative approaches will be used to explore the experiences of both low back pain sufferers and their primary care professionals. In the project's initial stages two members of the research team (BNO and HH) worked with users on the design and content of the study. User involvement was operationalized through the adoption of the focus group method. The outcome of the focus groups will be discussed, with particular reference to the tensions between involving users as co-researchers for design issues and their role as sufferers and health professionals who want to share their narrative accounts of low back pain. We draw conclusions as to possible approaches for user involvement in health services research design.

The experience of back pain

In this paper, we draw implicitly on the extensive body of sociological and anthropological research on pain. However, our discussions here focus specifically on low back pain. Recent papers highlight disjunctures between professional and sufferers' accounts of back pain^{14–16} and draw attention to the complex interrelationship between the biomedical paradigm's need to diagnose visible pathology and the private experience of pain.¹⁷ The central explanatory theme in much of this research is the apparent incompatibility of paradigms under-

pinning biomedical and lay interpretations of pain.

User involvement in research

A logical consequence of the growing interest in user involvement in health policy, delivery and evaluation^{18,19} has been an examination of the users' role in research.^{20,21} Developments in medical ethics and clinical governance have stimulated debates about the relevance and accountability of research. In the UK these various trends are pulled together under the umbrella of the NHS Research and Development strategy which places user involvement in research centre stage.²²

As this qualitative study aims to explore pathways of health-care in addition to experiences of low back pain it seems appropriate to extend the definition of users. We therefore not only include patients as users of health-care, but also health-care professionals who have particular perceptions of how patients use health-care provided by themselves or other health-care professionals. Moreover, the broader definition employed in this study incorporates the notion that both patients and professionals can be users of research results.

The arguments for involving users in all stages of the research process emphasize openness, quality, relevance and effectiveness, but little research has been reported on the added value of involvement, users' own perspectives and resources required.²³ This paper attempts to tackle some of the issues concerning the process of user involvement in research design, focusing in particular on the relationship between researchers' and users' expectations.

The Backpain Research in North Staffordshire [BaRNS] study

The BaRNS study design consists of a quantitative survey of all low back pain consultants at five general practices over a 1-year period ($n \sim 1400$). Baseline information for the study population will be collected using standardized validated tools, and patients will be followed-up

for 1 year using monthly questionnaires. The qualitative component is aimed at exploring the experiences of a subsample of sufferers, focusing on the way in which they live with low back pain and whether and how they use health (and other) services. The proposed methods are in-depth interviews at regular intervals, and observations. Sufferers' perspectives will be compared with a matched sample of general practitioners (GPs), physiotherapists, osteopaths and chiropractors who will be interviewed both about specific patients and their general perspectives of low back pain and its treatment. The study has received ethical approval from the relevant Local Research Ethics Committee.

Preparatory phase design

The purpose of the preparatory phase was first, to assess whether users could be involved in developing issues and questions for the main research study and, secondly, to gain feedback from users on the overall research design and the specific methods selected.

The focus group method was chosen as the optimal method for eliciting the views of user groups. This research approach is increasingly accepted in qualitative health research, especially because it brings together a group of individuals who can discuss and comment on 'from personal experience, the topic that is the subject of the research'.²⁴ In structured group discussions respondents' attitudes, feelings, beliefs, reactions and experiences can be explored making full use of the social interaction between group members.²⁵ When involving users in research design discussions, the focus group has the particular advantage of valuing people as experts and offering them a chance to work collaboratively with researchers.²⁶ Hoppe *et al.*²⁷ also argue that focus groups are suitable for the development of questions for interviews. A number of limitations have been reported in the literature.²⁸ For example, the influence of group dynamics on resulting recommendations will be discussed below in relation to our study.

Selection of focus group participants

For the GP focus group, six GPs (four males and two females) were invited from a range of different practice types (i.e. rural and urban group practices and a single-handed practice). The chosen practices were not involved in back pain trials or the pilot of the epidemiological questionnaire. Although five GPs responded positively, on the day, only three attended the focus group meeting.

For the health professional focus group, two physiotherapists were invited following the recommendations of the manager of the Combined Healthcare Physiotherapy Service. Two chiropractors, one aromatherapist and one osteopath were also invited. All practitioners responded positively, however, one chiropractor and the aromatherapist were not able to attend on the chosen date.

Patient recruitment was carried out using two strategies: first, patients attending a hospital back pain clinic and who met the inclusion criteria were invited to take part in the focus group. Two *new* patients and three *chronic* patients agreed to take part.* Secondly, five male and five female low back pain patients were selected from two age bands (30–44 and 45–59 years) by searching GP computerized consultation records. Contact was made via a letter from the GP practice. The focus group consisted of six patients (three males and three females), of whom only one person had suffered from back pain for <2 years. The decision to convene separate focus groups for patients, GPs and other health professionals was taken in order to minimize disciplinary barriers and to allow patients and professionals to talk freely about their experiences with back pain.

The focus groups were conducted by a facilitator (either BNO or HH) and followed a structured format. The first two groups focused on professional perspectives of low back pain,

*Inclusion criteria: *New*: (acute and subacute) back pain patients either following first visit to GP, or within the first few months of recurring symptoms. *Chronic*: patients who had consulted with back pain for more than 1 year.

interpretations of patients' experiences, diagnoses and treatment options. The patient group explored personal experiences of low back pain and its treatment. All groups were asked to identify areas for research and were invited to provide feedback on the methods proposed in the BaRNS study. Each focus group was tape-recorded and transcribed. Detailed notes were taken by the second researcher (BNO or HH with, on one occasion, an additional observer present) covering content and non-verbal behaviours. The two researchers analysed and coded all transcripts separately before comparing themes and concepts, which related to the experience of low back pain and to the research design.

Findings

We report the findings in two ways: first, we provide an analysis of the process of the focus group. The process is important in that it highlights ways in which agenda setting takes place, and thus helps to explain whether and how a focus on research issues was maintained. Secondly, we outline a number of themes that were discussed, some as a result of specific questions posed, others emerging through the group dynamics.

Each focus group started with a *brainstorm* of participants' perspectives on low back pain. The list of issues emerging served as the starting point for exploration as to whether each issue warranted further research, and if so, how it should be examined. However, rather than focusing on the research potential of each issue, group discussions tended to be dominated by an exploration of personal narratives. It became clear that participants did not make a distinction between research topics and their personal experiences and perceptions. This meant that in every focus group the participants emphasized their feelings, beliefs and experiences²⁵ and paid much less attention to a more dispassionate, structured approach that could lead to translating their personal experiences into research questions.²⁹

The GPs and health professionals presented a broad range of interpretations of people's

symptoms and explanatory systems alongside their own responses, as material for an exchange of views. They fully utilized the social interaction of the focus group, however, at no point in the discussion were their own views of patients or their professional practice raised as issues needing further research. Thus, although asked for reflective accounts that explicitly identified research issues, the participants offered their experiences as primary material for analysis instead.

Examples of the tendency to equate personal-professional experience with an objective account of the disease can be detected in data from all three groups. Little room was left for problematizing their own perspectives and therefore only a limited number of research issues were explicitly identified. The example concerns the classification of patients that professionals appeared to find important in terms of diagnosis and treatment. GPs presented the need to categorize unambiguously:

I suppose there's a kind of two groups that I see. I see the ordinary straight mechanical low back pain, maybe with radiating pain to the thigh, as being low back pain that responds well. But the good sciaticas [...] the real sciaticas don't seem to respond well to whoever they go to. And those are the ones that may have gone to various other people and come to us and have gone to the physio. And he sends them back saying 'getting no better'. I think they should have surgery immediately. (GP1)

This quotation illustrates the tendency to maintain professional paradigms and in the discussions no suggestion was made that sufferers' own experiences could be at variance with these classifications to the extent that professional interpretations should be deemed inaccurate.

In the patient focus group narratives were used to present personal histories, and served as anchor points to provide mutual support in the form of empathy and advice to individuals. Experiences varied considerably in the patients group and questions were regularly asked as to whether professionals' interpretations were consistent with their own. The first illustration

highlights the discrepancy between the personal experience of pain and a medical assessment that involved the application of certain criteria (e.g. paid work) to judge a patient worthy of attention:

A very arrogant [doctor] sat me down and said: 'What the bloody hell do you expect me to do if you are still working?' And because I was still working, obviously my back wasn't that bad. But it was. (Sufferer 1)

This incident marked the beginning of a long struggle to get access to further investigations and the operation that she believed would ease her pain. The dissonance between her invisible suffering and measurable pathology and pain continued. Her account indicated her perception that arriving at an agreed approach to managing her problems was not possible with the medical profession maintaining its inflexible application of clinical categories. Only when this patient found a physiotherapist, willing to conceptualize the back pain in lay terms, did she perceive a proper fit between her subjective experience and professional response.

In the second example the sufferer explained how the referral system only allows for a specifically defined route to appropriate help, and therefore lacks in responsiveness and individuality of approach:

Until recently, I have been one of the unfortunates who has to go through the doctor to get to the physio to wait weeks for an appointment that doesn't do you any good. When you go to the hospital, which takes months, and then you are better. As I say, now I am quite lucky. I have got this direct dial number and any problems with my back, it's straight to the hospital. We have cut out all the middle bits, which is far more effective because you get the treatment that you need at the time you need it. (Sufferer 2)

Achieving this direct access arrangement happened only after numerous episodes of severe back pain that she felt could have been alleviated with immediate professional help. The issue of waiting systems and times was interpreted by sufferers as a typical routinized response to their problems. All participants felt that they were not listened to as individuals,

because the medical paradigm and the health-care system tended to operate with a repertoire of symptoms and behaviours that did not easily recognize the variation and complexity of unique experiences.

Reflecting on the above discussion, it appears that the participants of all focus groups wanted to present their perceptions of low back pain and its treatment as valid explanations vis-à-vis their experiences. The health professionals considered their particular paradigms as given and at no stage in the discussions did they query their own world-view. Explanations by others, be it fellow health workers or patients, were viewed at best as interesting. The sufferers themselves were most explicit about the dissonance between professional and lay perspectives. What all focus groups had in common was their desire to get other parties to accept their understanding of low back pain. Consequently, the focus groups were primarily seen as fulfilling that purpose at the expense of explicitly formulating research questions.

The fact that the generation of research ideas became subordinate to the expression of participants' own experiences might be due to a number of factors. First, low back pain represents an affliction that is surrounded by considerable uncertainty as to its nature and treatment. This uncertainty gives rise to the need to impose order on one's experiences, and group discussions offer such an opportunity. Therefore, tension arises between the experiential exploration and the detachment required for formulating research topics. Secondly, focus groups make use of social interaction and need to find a balance between process and desired outcome (i.e. setting a research agenda). It may be that we did not fully negotiate on the outcome, and participants felt that the process was equally – if not more – important. Thirdly, each participant was regarded as an expert, and presentation of this expertise either took the form of a narrative account of experiences, or adherence to disciplinary paradigms such that the necessary consensus for defining research topics could not be achieved.

Key themes

The focus groups yielded a richness of themes and while these themes were not presented specifically as research questions, from the analysis of the transcripts it became clear that they represented significant concerns for participants. Identified concerns were often related to the ambiguity surrounding the experience of low back pain or to contradictions between different interpretations. We outline the most striking themes in this section.

Diagnosis and causality

The literature on pain highlights the particular dilemmas surrounding legitimizing symptoms and the limitations of medico-scientific criteria and methods.^{16,30} The GPs provided illustrations of their frustrations, each from their own vantage point:

I feel much more comfortable with the patient who comes in with low back pain and he or she sits down gingerly and you can see probably micro or macro trauma there, that there's some sort of mechanical thing – than the person who just bounces into the surgery, sits down and says 'it's me back doc'. And you examine them and you can't find anything at all – their history doesn't point to anything, it's all a bit vague. 'But I can't work with it'. And they're the ones that become more chronic, I think sometimes, and I find more difficult to cope with, I suppose. (GP1)

The absence of identifiable signs of physical damage made this GP solely reliant on the patient's account. Making pain visible through discourse crucially depends on the eloquence (both verbal and non-verbal) of the patient and the ability of the health-care professional to decode language into disease categories. If this process fails, the GP's feeling that he or she finds this type of patient difficult to cope with is the inevitable consequence.

Having their pain recognized and made legitimate through appropriate treatment was a major issue for sufferers. Almost every participant at the patient focus group mentioned that they had difficulty in gaining recognition of the

nature and degree of their pain. This is illustrated in the following exchange:

Sufferer 2: [...] I've got a full face of make-up on. I've done my hair – I look great – know what I mean? But I've had to get up at half past six this morning, have a couple of baths, have loads of drugs. Fiddle about with myself so that I look wonderful – because I look bloody awful when I get up in the morning because I've had no sleep. People look at you and if there's no plaster on it [...]

Sufferer 1: But why should you have a scar for somebody?

Sufferer 2: That's right. If you haven't got a bandage, or a plaster – something that people can see – that you have got something wrong.

While the discussion related primarily to their wider social circle rather than just health-care professionals, the meaning of pain remained difficult to convey to others. One of the GPs explained how she felt about this issue, echoing the same conundrum:

How do you prove that somebody hasn't got pain basically? If they say 'I've got terrible pain in my wrist' how do you prove that they haven't? It's very difficult with anything like that really. (GP2)

Proving the pain

The relationship between low back pain, its cause and symptoms, and sickness certification is complex. In a recent study, Palmer *et al.*³¹ argue that it is not necessarily an increase in physical symptoms that lies at the root of the increase in sickness absence. Instead they propose that 'cultural changes have led to a greater awareness of more minor back symptoms and willingness to report them, and this cultural shift may also have rendered back pain more acceptable as a reason for absence attributed to sickness'.³¹ The perspectives that professionals and sufferers presented in the focus groups illustrate the multiple layers in the meaning and validation of low back pain.

The discussion in the GP focus group illustrated perceptions of the socially constructed nature of patient pain:

GP 3: You say it used to be back pain, and now it's other types of pain.

GP 1: Well, forearm pain has become more of a problem probably in the last 10–15 years. Not a huge problem, but...

GP 2: Hmmm. There's been more about it in the media...and so that's how it's picked up, I think.

Facilitator: Yes, because it's now being seen as something that exists, isn't it?

GP 1: And that's related to occupation and therefore may be related to compo [compensation]. Well, there's a relation to that. You see that in people who've had whiplash type injuries in car accidents. They can have pain going for a long time.

While the above discussion shifts away from low back pain, the parallel is drawn in terms of the cultural and economic context of pain: health professionals perform an intermediary role by recognizing pain on behalf of the sufferer, and through the mechanism of professional validation they allow access to monetary compensation. This means that the act of diagnosis has meaning in both the medical and social domains, and it is important for the sufferer and professional alike that this is explicitly recognized.

The patient focus group recognized the importance of a diagnosis as validation, but they also emphasized their need to understand the cause of their pain. The search for causality is well documented in the literature^{6,32} and reiterated in the following exchange:

Sufferer 2: If you haven't got a cause, I think your own mind plays havoc and you think all sorts is going on. So, if you have a cause, and something to read about it and understand, then it does make you cope better, definitely.

Sufferer 4: I know how I caused it, but I haven't been told what I've done to it. That's why I'm waiting to hear...

Sufferer 5: Then you can accept it, when you know what it is. Then you can accept it better.

In the presented exchange the need for a diagnosis was acknowledged in terms of fitness to work. The search for causality was important for learning to accept and cope with the low

back pain, and for adjustment to a changed self-image. Sufferer 4 made it clear that he needed a more detailed understanding of what was wrong with him and any limitations this may place on his activities. The experience of *not knowing* was disempowering. The process of adaptation requires the construction of a framework that allows people to either live with the pain, or live around the pain.³³ Patient discussions highlighted a search for knowledge as to causality, effective treatments and boundaries to their activities.

Quality of life

In all three focus groups the impact of low back pain on people's quality of life figured prominently. The GPs discussed treatment protocols, access and patient education as the main avenues for managing low back pain and maximizing the quality of life of individuals. One GP emphasized the need to prevent patients getting 'stuck in the sick role' and saw quick referral to physiotherapists as the way to recovery. The emphasis was on speed of recovery and finding the most effective way to treat symptoms in order that patients could resume their normal lives.

The other health professionals elaborated on the above perspective by combining speed of recovery with a shared judgement by patient and therapist on 'an approach which they feel suits their bodies' (Osteopath). Patient involvement in the treatment process and defining their quality of life was seen as a two-way process. The therapists all emphasized a holistic perspective. The osteopath stated 'I start with the person in pain' and claimed to look at the totality of individuals' lives. Patient choice was also raised as an important issue and linked to people's expectations of recovery.

There is an increasing awareness that patients' own definitions of quality of life and desired outcomes should be taken into account. Kelson²⁰ argued that in many cases clinicians' or researchers' assessments do not reflect what patients would say or consider relevant. Not surprisingly, this was most clearly expressed

within the patient focus group. The following description illustrates clearly the differences between professional and lay expectations:

I must admit, I could have poked the [doctor] in the eyes when he blatantly refused to operate: 'Call this real bad pain? You go to work.' [...] 'Cos he keeps saying: 'You're too young to have these operations'. But I think when your quality of life is compromised... (Sufferer 1)

Understandably, the doctor made judgements based upon clinical practice and average eligibility criteria. In contrast, taking her own individual experience of pain as the starting point, the patient had formulated different expectations as to the quality of her life and desired interventions. Other factors seen as influences on patient quality of life included the balance between pain relief and side effects, self-help and professional treatments (traditional and alternative), long- and short-term improvements. In our in-depth interviews we will need to explore these various expectations and definitions of quality of life, and the ways in which they can or cannot be reconciled.

Conclusion

The main aim of this paper has been to discuss user involvement in research design, and we have concentrated on the issue of whether users explicitly formulate research topics or questions. The purpose of the focus groups was clearly stated to all participants, both in the letter of invitation and in introducing the discussions. However, it became obvious that the users perceived the focus groups as a forum for voicing their own experiences of living with or treating low back pain. Thus, a shift from setting an explicit research agenda to outlining an implicit one occurred. Structured consensus building methods such as the nominal group technique are tightly controlled by the facilitator, thereby limiting problems created by professional hierarchies and group dynamics.²⁸ However, while it can be argued that the researchers should have more strongly maintained the emphasis on the intended outcome, the process of exchanging

experiences yielded rich material for an analysis of important themes. In some way, the shift towards process can be seen as a sign of participants' involvement in agenda setting.

Reviewing the feedback forms that were distributed at the end of each focus group, the discussions were judged positively, particularly by patients. The literature emphasizes issues such as sharing experiences, validating points of view, exchange of ideas and problem-solving²⁵ that were reflected in patients' comments: 'Listening to other people talking about their experiences [...] and have people listen to me, has made myself feel more positive'; and 'It is so nice that someone 'cares' enough to find out about the indications and effects of pain [...] and this needs communicating'. The therapeutic effect of the focus group itself is reflected in the first comment, and the knowledge that further research will be shaped by this study in the second.

What does this tell us about involving users in research design? First, it is important to clarify and gain agreement about the objectives of the focus group. Our experiences suggest that agreeing a certain degree of distance from personal experiences may be a prerequisite for formulating a research agenda, particularly when discussing emotive issues such as pain and its treatment. Secondly, it might be difficult for participants to engage in a dispassionate discussion, and in that case, the material generated from discussions may serve to surface themes that could be translated into research topics, but this should be negotiated at the outset. Thirdly, it could be that the focus group format is insufficiently geared towards the production of a research agenda, and other approaches should be explored.

When directly asked about proposed research methods such as in-depth interviews or observations, all participants were able to give their opinion as to the appropriateness of each method. However, none of the participants suggested any change to the research design or methods. It may be that members of the three focus groups felt that the research approach was

appropriate, or alternatively, they may have felt that this was not within their area of expertise. In future, we need to explore in more detail whether training assists users in feeling equipped to question the appropriateness of research design and methods.

Two major issues have arisen from this preparatory study where research potential can be identified: first, the exploration of conflicting viewpoints, and secondly, the need to adjust our use of focus groups in the designation of research questions. Tensions and contradictions characterized the different interpretations of focus groups participants in this study. For example, patients' criticisms of not being listened to were contrasted with the sometimes rigid and rather limited beliefs of some health professionals. Research is necessary to explore how this apparent dissonance between professional and lay perspectives operates in the clinical encounter and the ways in which different expectations and beliefs can or cannot be reconciled.

Future research might also benefit from using a series of focus groups. The chance to recount personal experiences for group and/or researcher consumption appeared important to all user groups within this study, and should be the focus of a first session. A second group session could commence with the agreement of objectives and the definition of a research question prior to any discussion of possible research questions. This process could be aided using researcher summaries of experiences recounted in the first session.

This study has shown that the involvement of different types of users in designing research may be valuable for mapping out a territory. It remains unclear whether topics can be explicitly defined, but our study has demonstrated that rich material is produced by focus groups that serves as a robust basis for a qualitative study on the experience of low back pain. More reports are needed of actual user involvement and its outcomes so that further improvements can be made to achieve effective and real partnership between users and researchers.

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