

Developing patient-centred information for back pain sufferers

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Abstract

Objective To identify information needs among a group of back pain sufferers as well as the barriers that may prevent them from accessing this information.

Design Data were collected through the use of open, in-depth interviews, through contributions to the Norwegian Back Pain Association's online discussion list, and through a search of the literature.

Participants Norwegian back pain sufferers and their carers.

Main variables studied Information needs and barriers.

Results The informants described information needs that covered a wide range of topics, clinical, financial, emotional and social. Informants wanted to understand the cause of their pain and wanted information about existing diagnoses and diagnostic procedures. Informants asked for information about treatment alternatives, both within and outside the established health-care system, the effects of these treatment alternatives, their procedures, side-effects and costs. In addition, informants wanted information about the social and emotional effects of long-term pain; coping with everyday life; other people's experiences; and about welfare benefits and patient rights. Barriers to this information included the use of medical, legal and other jargon, doctors' lack of time, lack of communication skills, lack of knowledge about back pain and attitudes to back pain patients.

Conclusions To successfully address the questions and concerns of users, there should be an attempt to present information on as many of these topics as possible. Information should be presented in the user's own language, at several levels of understanding, and should include both evidence- and experienced-based knowledge.

Introduction

For most people, low back pain will be a short-lived experience. For one group, however, these problems will lead to long-term contact with

health-care providers and to greater or smaller limitations in their daily life. During this period, the back pain sufferer needs well-prepared and relevant information, but despite general agreement as to its importance lack of information is

still a common complaint.¹ In an attempt to address this problem the 'BackInfo' project was established in a collaboration between the Norwegian Back Pain Association and the Norwegian National Institute of Public Health. The project aims to develop an Internet-based information service for back pain patients that emphasizes relevance, accessibility and reliability. As a first step towards this goal, a qualitative study of information needs and barriers among Norwegian back pain patients was carried out.

Background

Written patient information is often based on doctor's assumptions of what patients want or need to know, assumptions that have often been shown to be incomplete or incorrect.²⁻⁴ This type of information can be described as medico-centred,⁵ in that it aims to encourage patients to follow what the doctor sees as rational sickness behaviour, and where information is distributed as a one-way flow from doctor to patient.⁶ In contrast, a patient-centred model of patient information aims to meet the patients' expressed needs for information,² and can be seen as a part of a growing demand for patient participation in health-care decisions.

This difference in approach mirrors the division between models of sickness as disease or illness. The disease model, most commonly associated with the explanatory models (EMs) of professional practitioners, relates to 'special theories of disease causation and nosology that are stated in an abstract, highly technical, usually impersonal idiom.' Illness, on the other hand, is associated with the EMs of the popular culture arena 'where sickness is most frequently articulated in a highly personal, non-technical, concrete idiom concerned with the life problems that result from sickness'.⁷

For individuals searching for information from other sources than their doctor, one potential source of health-care information is found in patient and consumer organizations. The knowledge that these organizations possess is often based on experience, as opposed to knowledge that is based on scientific evidence or

deduction,⁸ and can be described as representing the illness model of sickness. This type of knowledge may represent an important source of support for many people. However, information based on experience alone is not an adequate basis for medical decisions, and a study we conducted in 1997 suggests that many patient organizations are not in a position to provide reliable information about the effects of health-care interventions.⁹ In fact, a lack of ability to find, appraise and disseminate scientific evidence about health care is widespread among both health professionals and users, and medical advice, regardless of its source, is often based on a mixture of tradition, intuition and more or less well-designed research.^{10,11}

Another potential source of health-care information is the Internet. The Internet may have improved the accessibility of information, but problems of relevance and reliability still remain while new problems have been introduced. There are few rules to help the user tell commercial information from non-commercial information, and research from personal opinion.¹² A recent review of back-related information on the Internet concluded that most of these sites can be classified as commercial and that the quality is variable.¹³

Patient-centred and evidence-based health-care information

Not only are health-care users faced with a lack of information, the information that is available often has serious shortcomings with regard to relevance and reliability. Health-care users are thus left to make decisions that are uninformed and that may not harmonize with their own values. Health-care information that is evidence-based and patient-centred addresses information needs and concerns as experienced by the patients themselves and is the result of rigorous and systematic searches for knowledge.

The objective of the following study was to gain an understanding of the information needs of back pain sufferers and to explore the problems that people may have in accessing this information. Following the model of sickness as

illness, information needs are seen here as all of those needs for knowledge that arise as a result of the health-care problem.

Methods

The interviews

Earlier studies among other disease groups show that a person's stage of disease, age, socio-economic status and education level^{14,15-17} can influence his or her need for information. In an attempt to achieve a variety of responders, we made contact with Norwegian patients in several different treatment situations. One GP, one chiropractor, one physiotherapist, and two hospital doctors were asked to put us in touch with patients with chronic or acute low back pain with and without radiation. We also made contact with patients having back pain and with carers of patients having back pain through the Back Pain Association.

Open, in-depth interviews were used to collect data using the principles for qualitative interview technique as described by Weiss.¹⁸ Informants were asked to tell of their experiences with low back pain from its beginning and until the present day with an emphasis on their needs for information during this period. An interview guide was used and continuously developed in response to the interviews (see Appendix).

Fifteen back pain sufferers and four close family members of back pain patients were interviewed after which new themes no longer appeared to be forthcoming. The back pain sufferers had had back problems between 2 months and 30 years. A majority of them had several years of experience with back problems and should be defined as chronic back patients. The informants were between 24 and 65 years of age and lived mainly in and around Oslo. Ten of the informants were women and nine were men. Ten of the informants were members of the Back Pain Association.

The author carried out all interviews. Before the interviews, informants were assured of full anonymity and were asked to sign a consent form. Informants were also told that the inter-

viewer was a social scientist with no medical background. The interviews took place at the informants' homes, their place of work, or the interviewer's office, according to the preferences of the informant. Interviews lasted between 45 min and 2 h, and were completed when the interviewer or the informant felt that the topics had been exhausted.

After the interviews had been taped and transcribed, the author and one colleague, also a social scientist, carried out content analysis of the data, independently coding each interview according to information needs, themes that could be seen to influence these needs, and barriers to information. These codes were then compared, discussed, and merged. Quotes that are used in the report were chosen because they expressed common experiences, attitudes or topics or because they showed the width of experiences seen in this group. The informants have been given fictitious names in order to protect their identity.

The discussion list

Contributions to the Back Pain Association website's discussion list were also included as a source of data. Between January 1998 and January 2001, 475 contributions were made to the discussion list, all of which were included. Different degrees of anonymity make it difficult to know much about the contributors but it appears that they include about 200 different people, about half of whom are women. Discussion list contributions were analysed in the same manner as the interviews, and quotes that are used are also selected in the same way.

Permission to use contents from the discussion list was given by the Norwegian Back Pain Association, but informed consent was not obtained from individual contributors. Since the study was carried out, Eysenbach and Till¹⁹ have pointed to the ethical problems associated with the waiving of informed consent in the study of Internet communities and had the study been carried out today the author would have considered contacting each contributor individually.

Other studies

Systematic searches for other studies of information needs among low back pain patients were also carried out and qualitative studies of back pain patients' experiences of illness and health care were used in the development of the interview guide and to inform the present study.

Findings: information needs

What's wrong with my back?

I had hoped that it was a prolapse or something like that, something which could be seen in the pictures: 'There it is. There's the problem', but it isn't, they can't find anything concrete. [But] I wonder what this is. Is it an infection that's rubbing and infecting and irritating the nerve, why does it hurt all the way up my back, and well, what is it? I just want a diagnosis. (Georg, 32-year-old teacher.)

The back pain patients displayed a great need for some sort of diagnosis^{20,21} and called for information about existing diagnoses, their distribution, symptoms and prognosis. Informants also asked for information about existing diagnostic tests, both within and outside the public health system as well as information about what happens during these tests, what they can tell, what the difference is between them, and their price and availability:

What's the difference between an ordinary x-ray and a CT? For instance, can a prolapse be seen with an ordinary x-ray? And if not, what's the point of sending you to an x-ray if it seems like the patient has a prolapse? Are we talking economy here? (From the discussion list.)

Informants also wanted to understand the cause of their pain. Cause can be explained with reference to medical EMs based on knowledge or hypotheses about internal conditions in the body and this type of explanation was clearly of interest for several informants. However, back pain patients in this and other studies^{21,22} also make use of EMs that place their back pain in a larger context, referring to external factors such

as hereditary conditions, specific events or aspects of their work or spare time.

What can be done about my back pain?

The informants wanted to know which treatments exist, both within and outside the public health care system, what these treatments entail, whether they will work, their price and their accessibility. They also wanted to know what they could do themselves to get better and to avoid getting worse.

I have been diagnosed with a prolapse in level L4/L5. I have been recommended surgery and am going for a consultation at the hospital. As far as I've understood, they're talking about microsurgery. What does this mean? Do I have to stay in hospital for long? Do I have to rest for a long time afterwards? Do I have the right to childcare – financially? (My husband works shifts.) (From the discussion list.)

Questions to do with back surgery were particularly common and included the following topics: What type of surgery exists, who should undergo surgery and does it work? What are the prognoses for first, second and third operations? What will happen if the operation is not a success? Which hospitals carry out which operations, which hospitals are good at certain types of operations? Should I have an operation abroad, and if so, will the costs be covered by National Insurance? What happens during surgery and during the hospital stay? How long can I expect to be hospitalized? What happens after surgery, what type of follow-up can I expect, how can I relieve pain after surgery, and how quickly can I return to work?

What about medication?

Physical pain when I'm exercising doesn't bother me if I know that what I'm doing is right. But what frustrates me is when I suddenly get pains that I can't see any reason for. If I had clearly seen that 'you're bending all wrong now' or 'you were lifting something' or doing something like that I would have understood the cause of the pain, but just having unmotivated pain makes me nervous about

what's happening inside this body. (Dag, 47-year-old manager.)

Informants wanted to understand more about different types of pain and how best to respond to them.²³ Informants asked who should be using which medication, which medication can be used as alternatives for each other, and which medication should or should not be combined. They also showed concern about side-effects and the risk of drug addiction.

What about the social and emotional effects of long-term back pain?

You're not in a bad mood, inside you're not, but on the outside, you get so exasperated that you get this sour expression. You react quickly, you snap at people and it doesn't take much before things get too much for you. (Jane, 31-year-old warehouse assistant.)

Informants wanted to know more about common emotional reactions to pain and to interventions,¹ and also called for information about the connection between mental health and back pain. Informants also asked for advice about bringing up children, about how to relate to colleagues^{23,24} and about the effect of chronic pain on people's sex lives:^{23,24}

I am 45 years old and married to a woman who has a very bad back. At times she is bedridden for long periods of time and during these periods and for a lot of the rest of the time too, our sex life is bad. She is afraid that it will make her worse. No matter how considerate I am she doesn't want to have sex during these periods, and when she's back on her feet she's very careful. Is this common among back people/ladies? Do their natural needs disappear because of their problems? I know so little about this topic. She won't talk about it either. I hope that there's somebody out there who can share their experiences with me. (From the discussion list.)

How can I cope with every day life?

How to cope with every day life was also a common theme, and informants were eager to share their experiences:

I'm very adamant that when I get up in the morning I eat my breakfast and then I drink my coffee and then I go out. I cannot allow myself to start turning the TV on at 8 o'clock in the morning and sitting myself down on the sofa. I think its very important for all people who have a chronic illness that we, despite the fact that we hurt and that we mostly want to hide away and its raining outside and the weather is poor, I think its very important to get out, try and be sociable. Because then I think its easier to forget the pain. (Niels, 55-year-old lorry driver.)

What are my rights and what type of benefits am I entitled to?

Some informants asked for information about their rights as a patient, as a carer, or as a participant in a research project. Could they, for instance, apply for compensation for incorrect treatment, and would they receive legal aid?

Informants also had many questions tied to social security including which type of expenses will be covered, how to apply for different types of benefits, how long these applications will take, how decisions are reached and how to complain about decisions. Carers wanted to know whether their expenses would be covered.

What do other back pain patients do?

Throughout the material, informants showed an interest in the personal experiences of other back pain sufferers:

At the first meeting I was at in the Back Pain Association I met a person who had had exactly the same operation as me. And she had an extra disk in her back as well and she told me how she had exactly the same type of pain and went all woozy when she was in pain. So it was quite nice to hear that its not just me! At the same time you saw people who were much sicker than you were so and in one way you felt pretty healthy! (Dag, 47-year-old manager.)

Carers were also very interested in knowing more about how other carers coped and how they could be of more help.

Findings: barriers to information

As the study illustrates, chronic back pain can lead to needs for information about the practical, financial, social and emotional implications as well its medical aspects. The study points to a number of barriers that may prevent the individual from accessing or making use of health-care information.

Information from health professionals

Many of the questions posed in the discussion list and among the informants are questions that could have been answered by the person's doctor or other health professional. However, this and other studies confirm that doctors frequently fail to elicit the needs and concerns of their patients.²⁵ A number of circumstances may explain why information needs go unmet in the doctor-patient meetings:

Lack of communication skills

It would have helped if the doctors at least had talked to him, but my impression was that they would prefer not to. (Margrethe, 60-year-old housewife and mother of chronic back pain sufferer.)

In Åbyholm's study of Norwegian back patients,¹ participants criticize hospital doctors for their inability to communicate, their lack of listening skills, their arrogance, and their preconceptions. Informants in the present study voiced similar criticism, describing hospital doctors in particular as arrogant and inaccessible. These sentiments find support in a recent study of Norwegian doctors that suggests that there is a difference between hospital doctors and GPs in their views of patient information and autonomy.²⁶

Lack of knowledge, lack of time and lack of co-operation

Several informants saw GPs as more accessible than hospital doctors and occasionally used them to interpret information given by hospital doctors. On the other hand, informants often

had low expectations of their GP's knowledge about low back pain, and this may have led them to ask fewer questions. Informants also complained of lack of time during consultations, as well as a lack of co-operation and communication between different health professionals and institutions. The informants also pointed to their own lack of knowledge about their illness and about the health-care system as a barrier to gaining information: 'I don't know which questions to ask.'

Attitudes towards back pain patients

They're so sick of us ladies who come along with this sort of thing! There are so many of us and they don't know what to do with us, do they? And we complain and we hurt so much. One doctor has written about me 'her complaints are so massive ...' He could have written 'her problems' but it was the complaints that were the problem! Of course I was a pretty hopeless case when they couldn't figure out what it was. I heard from a friend of mine that her daughter, who's a doctor, is training to be a radiologist now because she can't stand all these old women who hurt all over the place! (Arnhild, 55-year-old teacher.)

Other studies have suggested that back pain sufferers in particular are not a popular patient group because of the difficulties involved in diagnosing and treating these patients.^{27,28} In addition, informants here and in other studies frequently refer to a fear that doctors and others view them as malingerers.^{1,29}

Medical jargon and information that comes at the wrong time

The doctor hadn't seen the x-rays, he'd only read what the radiologist had written. And he said, 'Well, you've read it yourself.' And I said, 'It's all in Latin! Even the priests have stopped speaking Latin, but you're still doing it!' Yes, but I had understood it, hadn't I? So I said, 'No, I haven't!' The only thing I'd understood was that it wasn't a prolapse so I thought, 'it's not that bad then. It's something that will pass then, it's all right.' (Laila, 61-year-old office worker.)

Questions about specific words and expressions are common in the discussion list, and

informants described the problems they had trying to understand their doctors and their journals. Informants also complained that information is given at the wrong time, because it has not been relevant at that time, because they have been on medication, or because they have been unprepared for it.

Health professionals' exclusion of lay models

A lack of awareness or acknowledgement of lay models of explanation may also represent a barrier to the fulfilment of information needs. While several informants called for more information about the cause of their pain, questions about cause are often answered with reference to medical EMs based on knowledge or hypotheses about internal conditions in the body. However, back patients in this and other studies^{21,22} also make use of other EMs that place their back pain in a larger context, referring to external factors such as hereditary conditions, specific events or aspects of their work or spare time.

Patients' attitudes to medication

And I'm very anti-anti, that's what they accused me of at the hospital when it comes to pain killers. I'd rather be in pain than eat poison. I'm afraid I'll get addicted to it. I have a brother who's an alcoholic, so I have that in the back of my mind. And I smoke like a chimney, and I can't stop smoking, so what if I get addicted to these tablets as well? (Niels, 55-year-old lorry driver.)

Attitudes and ideas among patients and the general public may also create a barrier to accessing information. The informants' concerns about medication, for instance, may lead them to ignore or distrust information. For some this concern was based on personal experience with unpleasant side-effects, while others had more vague ideas about risk of side-effects, addiction, and the concealment of damage or improvement to the back. A UK study suggests that similar assumptions about medication are widespread and that these assumptions may lead to inappropriate use of medication.³⁰

Information at the welfare office

They just tell you that they won't cover it. They don't care about finding out if you can get it covered somewhere else. (Berit, 44-year-old nurse.)

Problems encountered at the welfare office are very similar to those problems experienced during the consultation. Informants complain of staff arrogance, lack of knowledge and inconsistent advice, as well as a lack of time, jargon, and a fear the staffs view them as malingerers, factors that may all pose barriers to the information seeker.

Information from other back pain sufferers

Most informants gave high credibility to other back pain sufferers' experiences, and saw the value of being able to talk with or hear about others who have experienced the same problems. However, potential sources of information such as the Back Pain Association or web-based discussion groups were sometimes avoided. Some informants were sceptical to what they see as the 'moan and whine' culture that emerges when back pain sufferers get together. Others excluded this potential source of information because they did not view themselves as 'sick enough' or possibly because they were not ready to take on the role of 'chronic back pain patient' that membership in this type of group may assign to them.

Information from the Internet

While most of the informants used the Internet to search for back pain related information, few of them saw it as an important source. Informants complained of the lack of Norwegian-language information, and some found it hard to find their way around the information that was available in other languages.

Discussion

Strengths and limitations of the study

The literature search revealed no other studies that had as their primary goal the identification

of information needs and barriers among back pain patients although several studies did discuss topics that were of importance to this group. Studies of information needs have been carried out among other patient groups, with the use of different approaches. One approach is to present respondents with a list of information topics and to ask them to rate these topics or to indicate whether these topics are of important to them. Here, the danger of respondents rating most information needs as very or somewhat important to them has been pointed to in the study by Mills and Sullivan.³¹ In addition, the validity of questions and topics in questionnaire studies, i.e. the degree in which information topics are generated by researchers or whether they reflect what patients want to know, is also an issue.

The use of qualitative methods is particularly appropriate in the development of patient-centred health-care information as it enables us to elicit information needs as the sufferers themselves experience them. Through the collection of illness narratives it has been possible to gain a broad picture of information needs among back pain sufferers in several areas of their lives, and a number of topics other than clinical topics have been identified. The generalizability of this picture could have been made possible through a questionnaire based upon this study.

One possible shortcoming of the interviews is that informants have not related their experiences as they unfold, but from memory only. A majority of the informants were experienced back pain sufferers and information needs that have since been fulfilled may have been forgotten. An analysis of discussion list contributions may, however, have compensated for this shortcoming, as these contributions reflect back pain sufferers' needs for information as these are experienced.

Given that much of the data stemmed from online discussion groups, it is not surprising that a need for information about the experiences of others as well as a widespread use of the Internet was identified. We do not know enough about the discussion group contributors to tell whether or not they differ significantly from other back

pain patients. The widespread use of the Internet in Norway does suggest, however, that this group is not a minority. In addition, the themes raised in the discussion group contributions were very similar to those raised in the interviews, and the interviews served to give a broader context to these contributions.

Addressing information needs

Patient-centred, evidence-based information aims to address those questions that health-care users themselves want answered in a reliable and systematic way. The study illustrates that these questions may cover a wide range of topics, many of which have little direct connection to health care. In fact, information about issues such as welfare benefits, the ability to cope with everyday life, and the experience of carers may be as important as clinical information, especially for the chronically ill.

The study points to a number of issues that need to be considered if health-care information is to successfully address the questions and concerns of its users. Information about particular procedures can be greatly improved if these are placed in the larger context of the individual's life. Information about back surgery, for instance, is of most use if information about the effects of surgery is accompanied by information about its cost and availability. In addition, descriptions of what the patient can expect before, during and after the procedure, not only with regard to physical reactions, but also emotional reactions, practical circumstances, and patient rights should be included.

Information about cause should make use of EMs that refer to external factors such as lifestyle and hereditary aspects as well as the internal workings of the body.

Information about the effects or side-effects of treatment or medication should focus on outcomes that are of particular interest to the patient. In many cases, however, outcomes that are of interest to the patient will not correspond with those outcomes that have been included in scientific trials. Information about treatment options should also address methods that are

available outside the National Health Service, including alternative medicine, but again there may be little evidence available about their effect. The patient-centred, evidence-based approach may thus imply that the material highlights uncertainty and has the potential to frustrate its users with large degrees of information about what we do not know. For information services that wish to support informed patient choice, this is one possible side-effect that should be taken seriously.

The importance of experience-based knowledge as a source of support and advice that cannot be substituted by professional knowledge should also be acknowledged. While it should be clear to the user what is personal experience and what is based on scientific evidence, experience-based information should be integrated into the information service, for instance, through interviews with fellow sufferers and through discussion groups.

This emphasis on lay knowledge and on the broader context in which back pain takes place does not exclude the existence of an interest in and understanding of the disease perspective among back pain sufferers. For sufferers of chronic illnesses in particular these two realms of knowledge may be of equal importance and familiarity, and both types of information should be provided while at the same time clearly differentiated between. The information service should also acknowledge that individuals may have different levels of information needs, and information should be presented at different levels of complexity.

Addressing information barriers

The patient-centred approach leads us to the development of an information system that is holistic and inclusive with regard to the type of contents included. The Internet is particularly well suited for this type of approach as it enables us to link different types of information in a number of different ways. By developing an information system that is also free of charge, accessible around the clock, and written in the

user's own language, the BackInfo project hopes to remove a number of the circumstances that have prevented access to information.

In order to address the barrier to information caused by the use of medical jargon, and to ease the individual's understanding of, for instance, patient journals or welfare office statements, a glossary of relevant terms, with synonyms, related terms, and English translations should be included.

Barriers such as doctors' lack of time, lack of communication skills, lack of knowledge about back pain, and attitudes to back patients may be alleviated by the development of information that can be printed out and used in the consultation or as preparation before the consultation. Checklists with useful questions that can be used by the patient in common treatment situations or decision-making situations may also be of help. The success of this approach is partly dependent on our ability to develop information that is regarded as relevant and reliable by both health professionals and patients.

The study of information needs and barriers and the circumstances surrounding these has been an important step in the development of an information service for back pain sufferers. A service that meets these needs as far as possible is currently being developed (www.rygginfo.no), and continuously improved in collaboration with patient representatives and web site users.

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Appendix

Interview Guide (Translated from Norwegian)

- Let the informant know my background and tell them that back pain is not my area of expertise. Tell the informant that the interview will be used in the development of an information site for back pain sufferers.
- Ask the informant to tell me about his or her back problems from the time he/she started having problems and up until today. Mention that I am especially interested in the kind of information he/she feels he/she has needed during this time.
- For different situations/events described (that occur as a result of the back pain):
 - What kind of information has the informant wanted?
 - What kind of information has been offered (Conversations, brochures, etc.)?
- Has the informant used this information? What was good or bad about it? Was it understandable? Did it answer her/his questions?
- Has the informant tried to get hold of other types of information and, if so, where from?
 - For decision-making situations, for instance whether or not to undergo surgery – how was the decision made? How did the informant feel about the decision that was made?
 - Has the informant had any contact with the social security office?
 - Has the informant's back pain had an impact on family life?
 - Has the informant's back pain had any impact on working life?
 - Does the informant speak to other people with back problems?
 - Has the informant had any contact with the Back Pain Association?
 - How does the informant cope with the pain?
 - Does the informant use medication?
 - If the informant was to go through this again, would he/she have done anything differently?
 - Does the informant see him or herself as a typical back patient?
 - How does the informant see his or her future?
 - What is the informant's age and type of work?