



Clinical pain research

Exploring patient experiences of a pain management centre:
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ABSTRACT

Background and aims: To improve care and management of patients with chronic pain it is important to understand patients' experiences of treatment, and of the people and the environment involved. As chronic pain patients often have long relationships with medical clinics and pain management centres, the team and team interactions with the patients could impact the treatment outcome. The aim of this study was to elicit as honest as possible an account of chronic pain patients' experiences associated with their care and feed this information back to the clinical team as motivation for improvement.

Methods: The research was conducted at a large hospital-based pain management centre. One hundred consecutive patients aged 18 years and above, who had visited the centre at least once before, were invited to participate. Seventy patients agreed and were asked to write a letter, as if to a friend, describing the centre. On completion of the study, all letters were transcribed into NVivo software and a thematic analysis performed.

Results: Six key themes were identified: (i) staff attitude and behaviour; (ii) interactions with the physician; (iii) importance of a dedicated pain management centre; (iv) personalized care; (v) benefits beyond pain control; (vi) recommending the pain management centre.

Conclusion: The findings suggest that the main reasons that patients recommended the centre were: (i) support and validation provided by the staff; (ii) provision of detailed information about the treatment choices available; (iii) personalized management plan and strategies to improve overall quality of life alongside pain control. None of the letters criticized the care provided, but eight of seventy reported long waiting times for the first appointment as a problem.

Implications: Patient views are central to improving care. However, satisfaction questionnaires or checklists can be intimidating, and restrictive in their content, not allowing patients to offer spontaneous feedback. We used a novel approach of writing a letter to a friend, which encouraged reporting of uncensored views. The results of the study have encouraged the clinical team to pursue their patient management strategies and work to reduce the waiting time for a first appointment.

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1. Introduction

Pain, defined as “an unpleasant sensory and emotional experience described in terms of actual or potential tissue damage” [1], is an emerging health problem globally [2]. An estimated 19% of the

European population experiences chronic pain [3]. It is increasingly necessary to explore ways of improving patient care [4]. One of the recognized barriers to providing optimal care for patients with chronic pain is a lack of understanding about what patients expect from their management [5]. To improve this, patients' expectations and experience must be sampled, not only of treatment but also of the people and environment involved in treatment.

An important but understudied area is the influence on patients of the therapeutic team and the care provided. Considering their long relationships with medical clinics and pain management centres, it is quite possible that patients' interactions with the therapeutic team and experiences is represented in how they receive

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and respond to therapeutic interventions, and that in turn affects treatment outcomes. It is likely that patients' expectations differ from what is offered in clinics [6] although neither party may be aware of this [7]. Establishing a trusting relationship with the healthcare team involved may be an important part of treatment [8,9], particularly for patient self-management. Although effectiveness of treatments and overall patient satisfaction or adherence has been extensively studied [10–12], little is known about patients' specific experiences of pain centres.

Integrating patient views is regarded as vital to improving healthcare services [13,14]. Hence, obtaining those views in a way that is less restrictive than questions posed by treatment staff directly about care, should elicit a richer account from patients about their experience. Sharing these accounts with the clinical team provides feedback about the delivery of care to inform service development and management. In addition, although this pain centre has structured feedback about its cognitive behaviourally based pain management, there was little information about how patients appreciated the routine appointments.

2. Methods

2.1. Procedure

We asked patients to write a letter to a friend about the pain management centre, as an alternative to focus groups or interviews, because direct feedback to the treatment team or to a researcher is likely to inhibit criticism and to test letter-writing as a relatively simple yet open feedback method. This is a novel approach but based on sound psychological principles to elicit more honest answers that may also promote physical and psychological health of the participants [15]. It was designed to allow collection of rich data on patient experience without constraints of questionnaires or checklists, to build on existing knowledge of chronic pain patients' clinic experiences [16]. Patients attending the pain management centre for a second or subsequent appointment (to ensure there was sufficient experience to write about) were invited to write a letter to a friend on a single A4 sheet of paper, using the instructions: *Imagine a friend asked you the question, 'What is the pain management centre like?', and the letter started "Dear Friend"*. Participation was completely anonymous and patients were assured that their response was independent from their treatment. Patients deposited their completed letters in a box at the pain management centre reception.

2.2. Participants

To be invited to take part, patients had to be at least 18 years old, and have attended the pain management centre at least once before. One hundred consecutive patients meeting these criteria were approached, with an explanation of the study and an assurance of complete anonymity and independence from their treatment.

2.3. Data collection and analysis

All letters were transcribed into NVivo software [17]. NVivo software was used largely for categorizing the data collected into different codes and then themes. The steps described by Braun and Clarke [18] for conducting thematic analysis were followed. Thematic synthesis was chosen, as it is a tried and tested method in qualitative research [19], allowing identification of common themes across data sets, while preserving transparency between conclusions and research questions [19].

We adopted a phenomenological approach in our analysis to examine patients' views and opinions and the meanings they

attached to their experiences at the centre [20]. Transcribed data were read several times and similar concepts grouped together and assigned a code. Themes were developed by combining group of codes with similar meaning. This was done independently by two researchers who then compared and discussed their findings, following which the final themes were selected collectively by the team after several iterations.

3. Results

Seventy patients participated in the study; thirty declined. Reasons for declining included difficulties reading, writing or speaking English; lack of confidence in answering our question; and lack of time. Six key themes were identified: staff attitudes and behaviour; interactions with the doctor; implications of pain management centre being multidisciplinary; personalized care; benefits beyond pain control; and recommending the pain management centre. These are described below.

3.1. Theme 1: staff attitude and behaviour

Forty-two of the 70 letters (61%) described pain management centre staff attitudes and behaviour towards patients: staff were described as friendly, kind and helpful. Many patients reported that staff made them feel very comfortable, making their visit to the centre a positive experience.

"Everyone there is very kind and helpful"

"The personnel are so helpful and this puts you at ease straight away"

3.2. Theme 2: interactions with the doctor

Many letters described interactions with the treating doctor. Most reported receiving thorough attention, and described a high level of satisfaction about sufficient consultation time with the doctor, making them feel validated and heard. Patients compared pain management centre consultation length with other hospital outpatient and GP consultations, which were reported as short, leaving the patient feeling unheard and rushed.

"One of the most helpful aspects is the amount of time the staff allocate. You never get the feeling of being rushed through an appointment which is often the case with hospital consultants and GPs"

"They don't rush you and actually listen to you"

A second element of the consultation described was that the doctor provided a detailed explanation and information about pain, and answered patients' questions in a way that reassured them.

"Takes time to listen to me and explain every detail and are good at explaining my condition to me"

"I was very worried at first, but meeting the doctor and the explanations he gave me was reassuring."

3.3. Theme 3: importance of a dedicated centre for pain management

Patients described the pain management centre as "an oasis" for people with pain, where they were provided with positive and realistic management strategies within a holistic and supportive approach during and after treatment. Patients reported that unlike many other hospital departments or clinics, staff at the pain management centre had deeper knowledge about pain, showed greater acceptance of patients experiencing pain, and provided better care.

Some patients also reported that the pain management centre had not only helped them manage pain but also helped them to cope with despair and depression and improve their overall quality of life.

"You will find the staff at the clinic different – they meet people in pain and accept that it exists."

"It makes huge difference attending a specialist unit because the focus is so specific and the knowledge and understanding of the staff so helpful."

3.4. Theme 4: personalized care

Many patients commented on receiving personalized care and management, in particular being offered multiple options for treating their pain (including oral medication, injections, acupuncture, and psychological help), with detailed information about the treatments and possible side-effects, so that they could make an informed choice. For those patients with more than one type of pain, different treatment options might be offered for each condition.

"Not all treatments are suitable for all patients so the consultant works with the patient to develop a maintenance program using the treatments that work for them by means of a holistic approach"

"The pain management centre look at you and your pain as a whole"

3.5. Theme 5: benefits beyond pain control

A majority of the patients described positive change to their lives following attendance. Sixty-six participating patients reported improvement in their condition following treatment at the pain management centre, primarily alleviation of pain symptoms, but also other benefits such as increased physical functioning, better mental health, decreased reliance on drugs, and improved ability to work and quality of life.

"It has helped me live my life, coping with the pain, running a house, looking after a child of two and working part time"

"I know that without any doubt that this pain management treatment has not only saved me from a breakdown but also given me a much better quality of life"

3.6. Theme 6: recommending the pain management centre

Sixty-six of the 70 patients who participated specifically recommended the pain management centre to the friend to whom the letter was addressed:

"I can only hope you are referred to the pain clinic at Queen Square as I do not think you could be in better hands."

"I really recommend this centre and am thankful to everyone who helped in my care."

4. Discussion

The aim of this study was to understand how patients evaluated their treatment at the pain management centre in as honest a way as possible in order that this be fed back to the clinical team.

We identified six key themes. The first two, staff attitude and behaviour, and interactions with the physician, demonstrate the importance for patients of their interactions with the centre staff and physician. Feeling heard, believed, and the pain taken seriously were central to this, consistent with various qualitative studies of people with chronic pain in various other medical settings where

these experiences have been lacking [21,22]. This finding should be seen as an extension of the 'patient-provider relationship' [23], in which staff attitude and behaviour towards the patients can make patients feel supported, validated and comfortable, which is likely to improve treatment adherence and possibly treatment outcome.

In two further themes, importance of a dedicated pain management centre, and personalized care patients documented high satisfaction levels with the provision of a broad range of treatment options, highlighting in particular the range of treatment options besides pharmacotherapy, the detailed information provided about the options and involvement in their management plans, and care personalized to their needs and lifestyle, helping them to manage their symptoms and improve their function in everyday life.

Those who reported on outcome of treatment, in benefits beyond pain control, described a wide range of outcomes, consistent with patient reported outcomes, particularly improved quality of life, less reliance on drugs, and better mood that may go beyond usual clinical concerns [4,24,25].

Overall, whether they had received treatment or were at an early stage of assessment and treatment decisions, patients strongly recommended the pain management centre to their friends. Although none of the letters offered any criticism of care itself, the long waiting times for the first appointment were highlighted as a problem in eight letters of the 70.

The method of this study has some limitations. The design of the study did not allow us to ascertain whether some of the 30% who declined participation did so because they were dissatisfied or critical of their treatment or of the pain management centre staff, and because of anonymity, we cannot explore any demographic differences between those who agreed and those who declined. This limits generalization from our data. A further limitation is that themes were not crosschecked with participants for accuracy of interpretation of their experiences, also due to anonymity. Overall, we elicited little criticism, except of the waiting time, which was a shortcoming of the hospital system rather than of the pain centre in particular. A major strength of this study is its use of a freehand, confidential and anonymous method for patients to give their opinions.

5. Conclusion

To our knowledge, this is the first qualitative study to explore patients' views of a pain management service. The findings from the thematic analysis suggest that patients value each of the features of support and validation provided by the staff and physicians, provision of detailed information about the treatment choices available, personalized management with a focus on overall quality of life, in addition to pain control, and that for the large majority, this led them to recommend the pain centre without reservations to a friend. This underlies and validates the resources employed in delivering care to patients with long-term pain in three major areas: the time allocated for appointments, the attitudes of the staff, and the quality of the exchange between the parties.

6. Implications

Incorporating patients' perspectives is central to improving care. However, satisfaction questionnaires are limited in the information they provide, and it is important to try to elicit from patients a fuller account of their experience. This novel approach of writing a letter to a friend not only provides patient the freedom to report the full range of their experiences but the process of putting words to their feelings can benefit their psychological and physical health. In this study, the quality of care is highly valued but there may be

a trade-off between the length of a consultation and the time to a first appointment, which warrants research.

Ethical issues

The study was conducted at University College London Hospital's pain management centre as a patient experience survey (a form of clinical audit) for which no ethics approval was required [26].

Conflict of interest statement

All the authors declare that they have no conflict of interest.

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