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Clinical pain research

Exploring patient experiences of a pain management centre: A qualitative study

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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.

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