

Patient expectations for chronic pain management

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ABSTRACT

INTRODUCTION: In New Zealand, one in six people report chronic pain, but the literature indicates only a 30% pain reduction is typically achieved in about half of treated patients. Most patients expecting a cure of their pain, or even substantial pain reduction, are therefore likely to be disappointed. It is important to align patient expectations with this reality.

METHODS: This study analysed the responses of 250 patients referred to a Pain Management Centre to the free-text question: 'What are your main goals or reasons for attending the Pain Management Centre?' Free-text comments were analysed using ethnographic content analysis, an inductive approach in which the themes and subthemes are not predetermined, but emerge from the data during analysis, and thus reflect the issues of importance to patients themselves.

FINDINGS: Three themes emerged from the analysis: patients' desire to understand their pain, regain 'normality', and concerns about medication. Responses were divided into those with an expectation of cure, and those who seemed to be more accepting of their pain and who desired management.

CONCLUSION: Patients hope to return to what they perceive as normal and to have clear, relevant information about their diagnosis, prognosis and medications. Those desiring cure, or significant pain reduction, present more of a challenge to their general practitioners and the Pain Management Centre. When referring a patient for chronic pain management, there is a need to align patient expectations at the point of referral with what can realistically be achieved.

KEYWORDS: Chronic pain; pain management; patient satisfaction; qualitative research

Introduction

Chronic pain can be a disease in its own right, rather than being a symptom of an injury or disease, such as arthritis.^{1,2} In New Zealand, one in six people report chronic pain, defined as pain on most days for six months or more,³ or which extends beyond the normal period of healing.⁴ A 2011 review of chronic pain in the *Lancet*⁵ found that, '...of all treatment modalities reviewed, the best evidence for pain reduction averages roughly 30% in about half of treated patients'. This means most patients expecting a cure of their pain, or even substantial pain reduction, are likely to be disappointed. It is important to align patient expectations with this reality. One challenge for pain management is that patients differ in their expectations of treatment:

for some the expectation may be to eliminate pain; but for others, it may be to self-manage their pain during exacerbations.

Patient expectations for chronic pain treatment have not been extensively studied. Pain experiences differ depending on psychosocial, as well as biological factors. Evidence suggests that psychosocial factors influence the expectations patients have of treatments, and may in turn predict treatment outcomes.⁶⁻⁹ If patient expectations are not met, treatment outcomes may not be achieved.^{10,11}

The impact of chronic pain has been widely described, and includes physically debilitating consequences, such as sleep disturbances and fatigue, but also adverse socioeconomic and

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mental effects.^{4,5,8,12} Over the last half-century, conceptualisation of chronic pain has evolved from a purely biomedical approach to a biopsychosocial model.^{3,4,11} The traditional approach to injury or illness (the ‘medical model’) involves, sequentially, diagnosis, treatment and (hopefully) cure.¹³ However, as chronic pain cannot be readily cured,^{5,13} this approach offers little to those with the problem. Patients seeking relief from their pain can become trapped in a frustrating cycle of trial-and-error treatments. Patients with chronic pain and their clinicians, especially those not familiar with modern pain models, can struggle to reconcile beliefs about the potential for ‘cure’, with the reality of needing pain ‘management’.

This study, which uses a qualitative approach, was conducted in a tertiary level Pain Management Centre (PMC) in a major New Zealand city. The aims were to identify and enhance understanding of the expectations patients have before attending a PMC.

Methods

Before their first assessment at the PMC, patients complete a comprehensive ‘Intake and Outcome’ questionnaire. This includes quantitative measures of pain intensity and duration, medication use, and various psychometric measures. The questionnaire also asks patients to provide free-text comments to answer the question: ‘What are your main goals or reasons for attending the Pain Management Centre?’ Often the addition of open questions in questionnaires may be designed to help the patient feel ‘heard’, rather than to provide data for analysis, but there is no reason why these data may not be systematically analysed.¹⁴ Ethical approval for this study was granted by the New Zealand Health and Disability Upper South Regional Ethics Committee (Ref. URA/11/EX/032).

A sample of 250 patient questionnaires completed between January 2010 and November 2011 were selected from storage using computer-generated random number tables. Stratified or purposive sampling was therefore not required.

Analysis of free-text comments was completed using ECA (ethnographic content analysis), an

WHAT GAP THIS FILLS

What we already know: Evidence suggests that psychosocial factors influence the expectations patients have towards treatments, and that this may in turn predict treatment outcomes. If expectations are not met, treatment outcomes may be compromised.

What this study adds: Patients referred for tertiary pain management clearly identify the impact of chronic pain on their lives and a desire to return to normal functioning. They want to understand their condition, and particularly their medications. Some patients show a mismatch between their expectation for pain reduction or even cure, and the limits of what can currently be achieved in pain treatment. Primary care clinicians can help prepare patients referred for chronic pain management by providing appropriate information to modify their expectations away from biomedical approaches to pain.

inductive approach in which the themes and subthemes are not predetermined, but emerge from the data during analysis, thus reflecting the issues important to patients themselves.¹⁵⁻¹⁸ Free-text comments were initially transcribed verbatim onto an Excel worksheet along with patient gender, method of referral to the PMC, ethnicity, and average pain duration. Once entered, comments were read to gain familiarity with data content. On second reading, emerging keywords were extracted and coded. These codes were then sorted and grouped into descriptive themes, which were agreed by two of the investigators. A decision was made after the initial thematic analysis not to continue to link data to individual patients in any way, due to the large volume and lack of value in doing so. The quotes presented in the following section of this paper represent free-text comments from a wide range of the 250 patients included in the study.

Findings

Patient comments from a total of 97 males and 153 females were analysed in the study. The usual gender ratio of attendees is two-thirds women and one-third men. Of these patients, 18.8% entered the PMC from Accident Compensation Corporation (ACC) channels of referral, and the remainder were from Ministry of Health (MOH) referrals, including general practices and hospitals. ACC is the national accident insurer in New Zealand, which operates a 24-hour no-fault scheme for accidental injury. The predominant

ethnicity within the sample was New Zealand European (87.2%), and pain duration ranged from three months to 39 years. Comparing ACC-funded patients and those funded by MOH, no differences were identified in themes, gender, age, or pain duration.

The following themes were deemed to be most significant in relation to the research question: a desire to enhance understanding of their condition; living with pain and regaining 'normality'; and issues surrounding medication. These three themes will be dealt with sequentially below; but, threaded through all three themes, responses fall into two key groups. One group of attendees appeared to be somewhat accepting of the chronicity of their condition and desired optimising their pain management. However, the subtext in the responses of the other group was the continuing search for pain cure or reduction. It needs to be borne in mind that the PMC is the service of 'last resort', so the potential of other treatment modalities has usually already been exhausted.

Understanding pain

Whether seeking a pain cause, trigger or solution, the expectation that attending PMC would enhance patient understanding of their pain or diagnosis was common.

To seek an explanation for this pain.

Try to sort back pain which was not fixed when I had surgery... The solution... I get told a full fusion would be 'on the cards'—now they are saying no.

I have had severe ... injuries in the past two to three years which I feel have been under-diagnosed.

The fact I do not know what causes my pain and have received differing diagnoses makes it harder to understand for myself and others.

As PMC attendees have usually already been well investigated by specialists in other fields, attempts to continue to try to identify the root cause of pain are misguided. Implicit in the previous patient comments is the assumption that, if pain can be located and explained, it can be potentially cured; but the very diagnosis of chronic

pain supersedes the earlier belief that pain is due to pathology in the painful area. In the absence of identifiable tissue pathology causing their pain, it is explained to attendees that the underlying mechanism involved in their pain is probably abnormal function (i.e. hypersensitivity) of neural pathways carrying nociceptive ('pain') messages to, and processing them in, the brain.¹

The tone of the responses from those who seem to have developed some form of understanding and acceptance of chronicity is different.

Gain new understanding of my pain and when to push myself and when not to.

Learn to relax more. Manage pain when medication fails to work. Education to pass on to [my] partner so he can understand.

Here, there is a different relationship to the pain, and an apparent openness to forms of management that do not involve continued quests to diagnose and cure pain. While most attendees will likely want some 'explanation' of their pain, there is a difference between those who want explanation as a route to identifying cause and thence cure, and those who can accept and work with the explanation of its chronicity.

Living with pain and regaining 'normality'

Implicit in their attending PMC is that patients will 'have something done about their pain'. Two contrasting expectations emerged from this theme and were classified as subthemes: the expectation of living with pain versus that of living a pain-free life. These differences again suggest differing levels of acceptance in those referred to the PMC. Patients describing an expectation of living with pain commented on wanting to manage, control and/or cope with their pain.

To be able to make changes in my lifestyle to reduce and cope more ably with pain levels in order to maintain and increase my lifestyle as a wife/mother, as well as for individual benefit.

I'm hoping that I can gain some better pain management techniques in order to be more active and get some better quality of rest and sleep.

To be able to find ways to better cope with pain, and find ways to lessen it or make it more manageable.

In contrast, patients who used words such as ‘pain-free’, ‘eliminate’ or ‘fix’ described an expectation that, by attending the PMC, they would receive a solution or cure of their pain, and subsequently be able to resume a pain-free life.

To get my pain to a low level or pain free so that I can do what I want to do when I want to do it. I want to be pain-free!

To get through a day without feeling pain.

To stop feeling sore all the time.

To have the pain turned off.

Key to re-gaining some sense of normality was the desire to restore what was considered to be normal social, economic, emotional and physical functioning. Again, two contrasting types of responses were evident. On the one hand there were some patients whose expectation of normality involved the elimination of pain.

When pain peaks, I cannot walk for more than about 50 metres. My goal is to be reliably pain-free on an ongoing basis so that I can walk in the hills again, and so that I can ride a bike.

On the other hand, there were some patients who qualified their expectations with the use of words like ‘enough’ as in the quotation below. ‘Enough’ is hard to quantify, but does imply that attendees such as this one recognise that pain may be modifiable but remain.

Being pain free enough to enjoy my walking, reading, going on holiday, which we have not been able to do for some years.

As with regaining physical function, patients also expected that the PMC would help them regain social and economic function; for example, resuming work, school, childcare and social responsibilities.

I want to study to be a nurse. [I] was doing pre-nursing, but feel unable to return until I get pain relief. I have no life and live in pain.

The sense that lives were on hold pending elimination of pain is evident in the above quotation, whereas in those that follow there is a sense that the future is likely to hold a somewhat modified version of what was previously considered normal. This is evident in the use of terms such as ‘work of some description’ rather than the person saying that they wanted to get back to their old job. The reduction of dependence on others was also identified as significant. For many, the thought of a future relying on others to provide care and complete daily tasks was unwelcome.

So I can return to work of some description and take the pressure off my lovely wife, who has to work two jobs... To save my marriage and my family.

Even though the following quotation begins by commenting on the desire to locate a tissue-specific cause—a point commented on earlier in the paper as problematic in terms of acceptance and moving towards management—the beginnings of an understanding of chronicity are evident in the use of the word manage.

To find out what is causing pain... Find ways to manage/eliminate pain so that I can get back into normal life. Because of my young family, I try not to let the pain get in the way, and hope the children are not aware of how painful things are.

Medication

Expectations relating to medications, their use, long-term effects, and alternatives emerged as the third major theme. It is perhaps unsurprising that comments on medications make up a significant theme. For many people in the industrialised world, pain is something usually dealt with quickly and easily with over-the-counter analgesia. The thought that some forms of pain are unresponsive to any form of medication is unlikely to enter people’s heads. Many patients indicated in their responses that medications already tried were ineffective in easing pain.

Been given medication to help, but not working.

The tramadol hardly even takes the pain away.

Nevertheless, patients expected to be prescribed medication to alleviate their pain.

There must be some other medication that can fix the pain... I need to get the pain sorted so I can get back to work.

Again, there were some patients who did not expect cure from medications. There was an expectation that clinicians at the PMC would be able to confirm that their prescribed medications were as appropriate as they could be.

[To be given] right pain medication, as I know I will always have pain, and learning ways of coping with it.

Patients had a limited understanding of medications and their use in chronic pain. For some patients, the goal was to cease taking medication. This was especially the case when they were concerned about the long-term effects of analgesics, and did not want to rely on, or did not like having to take, prescribed medication. In the first quotation that follows, the patient wishes to develop a personal ability to manage pain to reduce pain relief medications. The second quotation suggest the patient is cure-focused, in that the implication is that the pain needs to be dealt with by the PMC, which will enable the person to 'get off the drugs'.

Being able to manage the pain without strong pain relief.

To get something done about the pain so I can get off the drugs.

For those patients who had to some extent come to terms with the chronicity of their condition, concerns about ongoing medication use were evident:

Knowing that I will have the pain for the rest of my life, I do have concerns as to what pain relief could be doing to my organs.

Discussion

This study describes the expectations patients brought with them on entry to a tertiary PMC, their understanding of their pain, and the impact it was having on their lives. Dealing with chronic pain is undeniably challenging for patients. They may be reluctant to share many of their thoughts

and feelings, to lessen the burden on their family and friends, to maintain these relationships.¹³ References to 'former selves' indicate that patients' experience with ongoing pain increases their awareness of their bodies compared to pain-free individuals whom they consider 'normal'.^{13,19} Crowe et al.²⁰ used the metaphor 'listening to the body and talking to myself' to illustrate the impact of chronic pain on people's sense of self. This was largely attributed to the unpredictable nature of their condition, which meant they were no longer able to function as they did prior to their pain. Being able to walk, stand, and complete physical and work tasks reliably are considered elements of physical function required to feel normal, and chronic pain often impacts on these.²¹ For those who expect a return to normality, however, there are of course severe challenges, not the least of which is that the concepts of normality or quality of life mean different things to different people.²² For some, the desire to regain normality may refer to the person being more in control of their situation, as opposed to pain being in control of the person.^{13,19,23} The clinical goal is to shift the balance of control from the pain to the person.

Whether patients expect cure, or if they have developed some form of acceptance of their condition, they want a better quality of life. The desire for enhanced understanding of pain has been repeatedly reported in the literature.^{11,23-26} In fact, the need for those with chronic pain to receive an explanation and clinical diagnosis has been noted as a driving force for seeking medical advice.^{11,26} Comparing the two groups of patients noted in the current study (those seeking cure, and those accepting chronicity and seeking better management), the first group place unrealistic expectations on the health system. When these expectations are unmet, further opinions are sought, although satisfaction is unlikely.^{11,23} 'Second opinions' can provide validation to patients and their relatives.²⁵ Interviews conducted by McPhillips-Tangum et al.²¹ revealed that the inability to regain physical function prompted repeated medical visits by people with chronic back pain seeking an explanation for their prolonged disability. This quest is usually futile.

When clinicians exhaust the treatment options available in their speciality, they often seem to

lose interest in the patient, which can lead to patients feeling abandoned.²⁷ This loss of interest, and the perceived failure of a health system to provide what is expected of it, has been found elsewhere^{13,19} and is reported to compound the negative mental and emotional impact of chronic pain.¹³ Not surprisingly, Liddle et al.²³ note that patients expected 'a comprehensive approach to their management incorporating understanding, listening and respect'. If patients are cure-focused, they may be likely to persist in feeling misunderstood, unheard and disrespected, because their expectations are unmet.

Patients who accept their pain as long-term, and that a complete cure is unlikely, show levels of accommodation of pain into their life.^{11,19,28} Campbell and Guy¹¹ described this as 'the ability to persevere despite the pain and to remain driven towards amelioration of it'. Consistent with those in our study who were more accepting, they found that such patients placed an expectation on themselves to overcome their pain, rather than placing the expectation of treatment and recovery entirely on the health system. Some of the patient quotes Campbell and Guy included were:

- 'I won't let it beat me';
- 'It's down to your attitude'; and
- 'It's basically down to people's will to manage and cope'.¹¹

May¹⁹ also found that patients were eager to learn methods and techniques to manage/control their pain themselves.

As indicated previously, the role of analgesics of various types in the day-to-day management of pain makes it predictable that comments on medication featured as a significant theme. Petrie et al.²⁴ found that patients on their first visit to a pain clinic expect a change in their previously prescribed medication. For the 'accepting' patients, this expectation will likely be to optimise medication, whereas for those still seeking a cure, pain elimination remains the goal. Bozimowski²⁹ reports that lack of knowledge regarding medication and its role in pain management is a key barrier to facilitating positive patient outcomes. Medication use has proven controversial amongst people with pain. In their qualitative study,

the findings of which resonate with this study, Campbell and Cramb¹³ found that patients felt discontented with the prescription of medication, their lack of involvement in decision-making on their medications, and were concerned about prolonged use of medication. Such issues in relation to medications present clinicians with another potentially challenging area to negotiate.

Addressing patient expectations, especially regarding pain reduction, is essential, lest dissatisfaction from unmet expectations further exacerbates physical, social and mental/emotional impacts of the patient's pain. However, as discussed, the potential for people to receive clinically meaningful pain reduction through medications is limited, which is often not recognised at the time of initial consultation. At the same time, although in this study many individuals identified a desire to 'get on with life', this is often predicated upon the notion that they will be able to do so if their pain is reduced.

The task of meeting the expectations of patients referred for chronic pain management is difficult, but it is much more difficult when patients come expecting a cure. Biomedical approaches to illness involving examination, diagnosis and treatment shape patient expectations that they will receive a tangible 'fix' for their condition.¹¹ The biopsychosocial approach adopted by the PMC can be very challenging, particularly for those patients who expect cure and eschew all but biomedical approaches. It is these patients who signal early on—when they complete the initial form on which this paper is based—that they expect a cure who are likely to be disappointed, and who may remain very challenging patients for general practitioners. Some patients do manage to transition in their expectations from a cure to an acceptance and management focus, and it is this potential that needs to be explored. Unless patient expectations can be aligned with what is achievable at the PMC, then outcomes are likely to be even more limited.

When referring a patient for chronic pain management, there is a need to align patient expectations at the point of referral with what can realistically be achieved. In the face of the intractability of chronic pain, and its potential for

high levels of distress and disability, the importance of focusing on pain management, as opposed to pain cure, is crucial. In order to modify patient expectations of what the PMC can offer, advising patients of the limitations of pharmacological approaches for pain relief before referral to the PMC is recommended. Additionally, patients should be encouraged to view the referral as a means to understand their pain, and to develop skills to cope more effectively so they can 'get on with life' despite the presence of pain.

In the general practice setting, this involves several interlocking actions. The first is to consider one's own understanding of chronic pain. It is ultimately unhelpful to the patient if the primary care physician has a persistent belief in a biomedical fix³⁰ for what is, like asthma, a chronic condition. The second is beginning to prepare the patient for managing pain by using 'management' rather than 'cure' language during consultations. Finally, if a general practitioner remains uncertain as to whether all biomedical avenues have been exhausted, the patient should probably not be referred to a PMC.

Limitations of this study are that the data used in this study was drawn from patients referred to a tertiary pain management centre, so caution is advised before applying the findings from this study to all patients with chronic pain seen in primary care. Strengths of the study, however, include that the study sample was drawn at random from a large cohort of patients referred to the PMC, and that the sample was representative of this larger group in terms of age, gender, pain duration, and compensation status.

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COMPETING INTERESTS

None declared.