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MASTERCLASS

Patients' experiences of living with persistent back pain

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Abstract *Objectives:* This Masterclass discusses findings from a growing body of qualitative research studies that have investigated the subjective experience of having persistent non-malignant low back pain. These studies have found that people with experience changes in self image, personal relationships and life roles. They have also reported on how subjectivity affects the therapeutic relationship, what patients have found helpful in dealing with healthcare professionals, and what it is like to go through a healthcare system for a pain that may not be curable or even diagnosable. The findings are of great importance for clinicians who wish to provide person centred care for patients with persistent low back pain, so this Masterclass ends with key lessons for practitioners.

Introduction

The International Association for the Study of Pain refers to pain as "an unpleasant sensory and emotional experience".[1] Several terms in this definition relate to deeply subjective aspects of the pain experience, which have been examined in a growing body of qualitative research studies. This type of research may investigate for instance what it is like for a person to experience and live with pain, or what social, psychological and interactive processes are utilised by patients to cope with their pain. Unlike most scientific research, it does not seek to categorise, measure or predict. Many different approaches have been developed over the years, such as phenomenology, grounded theory, narrative research and ethnography. Researchers choose their approach and match it to the issue under investigation. A number of recent papers have introduced the principles of qualitative research approaches to manual

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therapists.[2–4] Texts such as Creswell[5] explore the differences between five common approaches to qualitative research.

Qualitative research can be described broadly as 'any type of research that produces findings not arrived at by statistical procedures or other means of quantification'.[6] It uses inductive reasoning to generate general conclusions from specific data.[7] Qualitative researchers attempt to 'make sense of, or interpret, phenomena in terms of meanings people bring to them'.[8] In order to do so, they typically develop close contact with purposively selected participants, using data collection methods such as in-depth interviews and written narratives.[9] The attitude required of the researcher in collecting and analysing data may be described as 'empathic neutrality'.[9] While low numbers of participants and a degree of subjectivity prevents qualitative research from being generalisable, it can provide an understanding that can be transferred to other people or settings.[7]

This Masterclass reports on qualitative research studies which have investigated what it is like to have persistent back pain. These studies have found that persistent low back pain may be associated with changes in self image, personal relationships and life roles. They have also reported how healthcare professionals may be perceived by patients, what may help or hinder patients to deal with their back pain, and what it is like to go through a healthcare system which at times can offer only limited explanations and solutions. These subjective perspectives influence how a patient presents to and interacts with their clinician, so qualitative research provides information which can be clinically useful.

The studies included in this paper were identified through literature searches which combined 'pain' and 'back pain' with 'subjective' and 'qualitative', going back 20 years. Further studies were found by following up references in the initial papers. The included studies identified themes from interviews and focus groups with participants suffering with back pain for at least 3 months and often for several years. All provided a clear description of their participants and methods, although specific reference to age or gender was generally absent. Several studies were carried out from a specific theoretical position, typically phenomenology or narrative analysis, while others applied thematic analysis more pragmatically (see Creswell [10] for a comparison of qualitative approaches). Participant numbers were low (generally between 6 and 16) as is common in qualitative research, although one study performed a qualitative analysis of 133 responses to an open survey question which asked participants to describe their back pain in their own words.[11] As a consequence of the small sample sizes and methodologies involved, the themes identified by researchers could not be generalised, but they provided rich material for reflection on the subjective perspective of the patient. Studies discussing pain from a professional or non-patient perspective were excluded.

Becoming a person with persistent pain

An initial failure to find a cure for back pain can lead a patient to a series of examinations, tests and treatments, interspersed with dissatisfying and long waiting times.[12,13] As a consequence, patients may feel trapped in the healthcare system and experience feelings of helplessness and injustice.[14] Hope of a solution can keep them searching for a long time, and the realisation that their pain may never go away is likely to arise as a result of repeated treatment failures.[11,13,15–17] Patients have described a gradual decline of hope of a cure, together with the development of feelings of hopelessness, despair, and anxiety about the future.[11,15]

Patients with persistent pain wish to have a definitive diagnosis because it may lead to an effective treatment,[18] but even positive investigation findings may not yield a cure and thus contribute to feelings of hopelessness.[15,19] A diagnosis may also be a way of having the pain legitimised, which is important to back pain patients who feel vulnerable to other people's doubts about their sincerity.[11] As a consequence, negative investigation results may be only partially reassuring.[11] They also leave some patients wondering why they are in pain.[15] Relief over the absence of serious pathology can paradoxically combine with self doubt, with some patients wondering whether their mind may be creating the pain.[19]

While some patients refuse to give up the search for a diagnosis and potential treatment, many eventually come to accept that their pain has become a permanent aspect of their life.[15,20] Although this acceptance may bring positive rewards long-term,[21] to patients it can feel initially as if they are giving up the fight, resigning themselves to a life with pain and letting the pain 'win'.[22] Provision of a rational explanation for the origin and persistence of the patient's back pain, together with appropriate support from clinicians, friends and relatives, can help patients to come to terms with their situation.[15,23]