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INTRODUCTION

The International Association for the Study of Pain refers to pain as “an unpleasant sensory and emotional experience” (Merskey et al. 1994). 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 therapists (Petty, Thomson, & Stew 2012a; Petty, Thomson, & Stew 2012b; Thomson, Petty, & Scholes 2014). Texts such as Creswell 2013 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’ (Strauss & Corbin 1998). It uses inductive reasoning to generate general conclusions from specific data (Teddlie & Tashakkori 2009). Qualitative researchers attempt to ‘make sense of, or interpret, phenomena in terms of meanings people bring to them’ (Denzin & Lincoln 2005). 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 (Snape & Spencer 2003). The attitude required of the researcher in collecting and analysing data may be described as ‘empathic neutrality’ (ibid). 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 (Teddlie & Tashakkori 2009).

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 2007) 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 (Vroman, Warner, & Chamberlain 2009). 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 (Cooper, Smith, & Hancock 2008; Walker, Sofaer, & Holloway 2006). As a consequence, patients may feel trapped in the healthcare system and experience feelings of helplessness and injustice (McParland et al. 2010). 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 (Corbett, Foster, & Ong 2007; Iles et al. 2012; Liddle, Baxter, & Gracey 2007; Vroman, Warner, & Chamberlain 2009; Walker, Sofaer, & Holloway 2006). 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 (Corbett, Foster, & Ong 2007; Vroman, Warner, & Chamberlain 2009).

Patients with persistent pain wish to have a definitive diagnosis because it may lead to an effective treatment (Nielsen 2013), but even positive investigation findings may not yield a cure and thus contribute to feelings of hopelessness (Corbett, Foster, & Ong 2007; Toye & Barker 2010). 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 (Vroman, Warner, & Chamberlain 2009). As a consequence, negative investigation results may be only partially reassuring (ibid). They also leave some patients wondering why they are in pain (Corbett, Foster, & Ong 2007). 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 (Toye & Barker 2010).

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 (Corbett, Foster, & Ong 2007;Osborn & Smith 1998). Although this acceptance may bring positive rewards long-term (Toye et al. 2013), 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' (Harding et al. 2005). 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 (Corbett, Foster, & Ong 2007;Lundberg, Styf, & Bullington 2007).

IMPACT OF PERSISTENT PAIN ON THE INDIVIDUAL.

Patients with persistent back pain have described a heightened awareness of the parts of their body which are painful, dysfunctional or numb (Campbell & Cramb 2008;Osborn & Smith 2006). These aspects of their physical being, previously taken for granted, now feel different and demand constant attention (Osborn & Smith 2006). The coordination of painful body parts also requires increased effort (ibid). As a consequence, patients may experience painful body regions as not belonging to them (Osborn & Smith 2006;Snelgrove & Lioffi 2009). Additionally, constant attention to the way activities are carried out is likely to take away the ability to be spontaneous (Crowe et al. 2010;Snelgrove & Lioffi 2009).

Persistent back pain may lead a patient to develop new character traits and behaviours (McParland, Eccleston, Osborn, & Hezseltine 2010;Smith & Osborn 2007). Analogous to the changes in the relationship they have with their body, the new psychological traits may be experienced as alien (ibid). Internally patients may regularly experience negative emotions such as anger, depression, fear and a sense of chaos (Lundberg, Styf, & Bullington 2007;Snelgrove & Lioffi 2009). As a consequence of the alterations in body perception, body function and internal experiences, patients may face a constant internal struggle to maintain a sense of physical, mental and emotional integrity (Osborn & Smith 2006;Smith & Osborn 2007;Toye & Barker 2010).

The patient's sense of integrity may be threatened further by the fact that the pain itself can feel as if it develops 'a mind of its own', ie it can fluctuate unpredictably and behave as if it is independent of the patient (Corbett, Foster, & Ong 2007;Crowe, Whitehead, Gagan, Baxter, Pankhurst, & Valledor 2010;Osborn & Smith 1998;Snelgrove & Lioffi 2009). This can make it difficult to know what to do for the best, leading to a sense of helplessness and being at the mercy of what the pain 'decides' to do next (ibid). It can also make it difficult to plan activities, both on a short-term and a long-term basis (Corbett, Foster, & Ong 2007;Patel, Greasley, &

Watson 2007). Patients may thus be forced to give up work and valued leisure activities (Corbett, Foster, & Ong 2007;Osborn & Smith 1998;Patel, Greasley, & Watson 2007). The loss of activities and social roles which previously contributed to the patient's sense of self worth, is likely to add to emotional distress (Harding, Parsons, Rahman, & Underwood 2005;Vroman, Warner, & Chamberlain 2009). It can also bring uncertainty and fear about future prospects (Corbett, Foster, & Ong 2007;Lundberg, Styf, & Bullington 2007) and contribute to a sense of loss, unfairness, and life being suspended (Bunzli et al. 2013;McParland, Eccleston, Osborn, & Hezseltine 2010;Vroman, Warner, & Chamberlain 2009).

Even patients who manage to continue working despite their pain describe being fearful about their long-term future (Corbett, Foster, & Ong 2007;Holloway, Sofaer-Bennett, & Walker 2006;Walker, Sofaer, & Holloway 2006). They may feel under pressure to provide legitimate explanations, which is difficult in view of the aforementioned lack of specific medical findings and negative responses to treatment (Coole et al. 2010;Osborn & Smith 1998;Toye & Barker 2010). Some attempt to manage their back pain without drawing unwanted attention to themselves, for example by using up their annual leave rather than taking sick leave (Coole, Drummond, Watson, & Radford 2010). Increased communication between patient, employer and healthcare system may help to overcome vocational challenges, but patients report that the role of GPs is often restricted to the provision of medication and sick notes (Coole, Watson, & Drummond 2010).

RELATIONSHIPS WITH OTHERS

Several studies report that persistent pain can lead to social isolation for several reasons, in addition to those described above. In some studies, patients with persistent back pain have described how their pain has led to a judgemental attitude and a loss of empathy towards others (McParland, Eccleston, Osborn, & Hezseltine 2010;Smith & Osborn 2007). They may also find it difficult to keep their emotions under control and not get short-tempered with people around them, including loved ones (McParland, Eccleston, Osborn, & Hezseltine 2010;Smith & Osborn 2007). In order not to hurt others, patients may choose to, or feel forced to, withdraw from social interaction (Smith & Osborn 2007).

Fear of being judged also makes patients reluctant to engage with others (Smith & Osborn 2007;Vroman, Warner, & Chamberlain 2009). Moreover, pain, loss of physical function and reduced concentration can make it difficult to continue sharing activities with friends and relatives (Walker, Sofaer, & Holloway 2006). This may be exacerbated if a patient experiences a tension between seeking support from others and being a burden to them (De Souza & Frank 2011). The need to share experiences may conflict with the fear that doing so may in fact turn others away (Campbell & Cramb 2008). As a consequence, personal relationships are likely to change or even come to an end (Walker, Sofaer, & Holloway 2006), adding to the

patient's social isolation and sense of loss (Campbell & Cramb 2008;Smith & Osborn 2007;Walker, Sofaer, & Holloway 2006).

RELATIONSHIPS WITH HEALTHCARE PROVIDERS

In order to have their symptoms legitimised, patients may be at pains to give a very clear account of their symptoms when visiting healthcare practitioners. Unfortunately several studies report that patients feel that these professionals often do not allow enough time for discussion, lack understanding of their situation, and come across as skeptical and disbelieving (Campbell & Guy 2007;Harding, Parsons, Rahman, & Underwood 2005;May, Rose, & Johnstone 2000;Snelgrove & Lioffi 2009;Toye & Barker 2010;Walker, Holloway, & Sofaer 1999). It must be noted that there is a bias towards state healthcare settings in these studies. Patients suggest that healthcare practitioners' initial enthusiasm tends to give way to a loss of interest when treatments fail to deliver the anticipated results (Walker, Holloway, & Sofaer 1999). As a consequence, patients can feel written off, stigmatised, disbelieved and even blamed by practitioners, giving rise to feelings of anger, frustration and despair (Corbett, Foster, & Ong 2007;Holloway, Sofaer-Bennett, & Walker 2006;Osborn & Smith 1998;Walker, Holloway, & Sofaer 1999). A clinician's inability to provide a clear explanation for the pain is likely to add to this distress (May, Rose, & Johnstone 2000;Vroman, Warner, & Chamberlain 2009).

In an attempt to get their symptoms validated, patients can feel under pressure to appear unwell in front of healthcare practitioners (Osborn & Smith 1998;Toye & Barker 2010), but this is difficult because persistent pain can fluctuate from day to day (Holloway, Sofaer-Bennett, & Walker 2006;McParland, Eccleston, Osborn, & Hezsetine 2010;Toye & Barker 2010;Vroman, Warner, & Chamberlain 2009;Walker, Holloway, & Sofaer 1999;Walker, Sofaer, & Holloway 2006;Werner, Widding Isaksen, & Malterud 2004). Patients may therefore feel forced to exaggerate their symptoms or disability, in order to avoid being labelled as psychogenic or fraudulent (Glenton 2003;May, Rose, & Johnstone 2000). On the other hand, experience may also teach them that healthcare practitioners do not find it easy to deal with patients who come across as 'too unwell' (Osborn & Smith 1998;Toye & Barker 2010). As a consequence, they feel obliged to act according to what they think is most likely to engage the clinician and generate the desired response (Osborn & Smith 1998;Toye & Barker 2010). Similar issues play a role in assessments for benefits or compensation (Walker, Holloway, & Sofaer 1999).

Several qualitative studies report difficulties experienced by patients with persistent back pain, but some have investigated what patients with persistent back pain find helpful in a consultation. Although some patients admit that they prefer to hand the responsibility for their care to their clinician (Cooper, Smith, & Hancock 2008), others value a sense of partnership and mutual understanding, in which the patient's experience and insight is paired with the expertise of the clinician in order to

establish the best way forward (Slade, Molloy, & Keating 2009). They appreciate clear explanations of tests and findings before, during and after the examination, in terms that they can understand (Cooper, Smith, & Hancock 2008; Kidd, Bond, & Bell 2011; Laerum, Indahl, & Skouen 2006; May 2001; Slade, Molloy, & Keating 2009). In other words, they want the clinician to explain what the aim of the examination is, talk them through the tests as the examination proceeds, and share their conclusions with the patient afterwards (ibid). Patients also wish to understand their pain, have their fears allayed and be given a way forward according to their individual needs (Cooper, Smith, & Hancock 2008; Kidd, Bond, & Bell 2011; Laerum, Indahl, & Skouen 2006; May 2001). This may conflict with some rehabilitation settings, in which patients are seen in groups with limited scope to tailor exercises and self management strategies to the individual (Cooper, Smith, & Hancock 2008). Finally, access to the same practitioner for future consultation or a telephone line is valued by patients (Cooper, Smith, & Hancock 2008; Cooper, Smith, & Hancock 2009).

LEARNING TO COPE

A systematic review of qualitative studies by Toye et al. (2013) investigating patient experience of chronic non-malignant pain identified several ways in which patients may progress, some of which have been touched on above. Coming to terms with the fact that there is no cure can help patients to move on, even if it does not stop them from grieving for what they have lost (ibid). This includes developing a new relationship with their body by 'listening' to it and learning to respect it (ibid). Doing so can help patients to take back control and regain activities despite the pain (Liddle, Baxter, & Gracey 2007; Vroman, Warner, & Chamberlain 2009). The realisation that they are the expert in the management of their back pain can also help patients to manage their reliance on others, for instance by being selective about when and how to ask for help from people around them or healthcare practitioners (Toye, Seers, Allcock, Briggs, Carr, Andrews, & Barker 2013). This may include being clear and honest about abilities and limitations, and sharing experiences with other people (ibid). Finally, the provision of pain management strategies can help to restore the patient's sense of control and ability to plan ahead (Holloway, Sofaer-Bennett, & Walker 2006; Patel, Greasley, & Watson 2007; Walker, Sofaer, & Holloway 2006).

CONSIDERATIONS FOR PRACTITIONERS

On the basis of studies which have investigated the subjective experience of having persistent low back pain, clinicians may wish to consider the following.

- The way a patient presents in clinic is influenced by a range of factors, including the way their sense of their body and personality is affected by their pain.
- Patients may wish to understand why they have ongoing back pain, especially if the results of their medical investigations are negative or the response to

treatment is not as anticipated. A practical understanding of pain mechanisms and the ability to explain these to patients are therefore imperative for clinicians (Main.CJ 2009). Acceptance of pain as non-threatening has been shown to require a full explanation which includes all factors relevant to the patient (Dowrick et al. 2004). Interestingly, patients have been shown to understand and retain more information about pain mechanisms than healthcare professionals may realise (Moseley, Nicholas, & Hodges 2004).

- Some patients feel helpless with regards to their back pain, its impact and healthcare. Apart from explaining possible causes and factors maintaining their pain, practical pain management strategies tailored to the individual can help to restore a sense of control and autonomy. A range of self-help materials is available on the internet and in the form of CDs, books and support groups.
- Patients with persistent back pain have reported a loss of their sense of physical integrity, so treatments which reinforce body awareness, coordination and general movement may be helpful.
- Patients wish to have a chance to tell clinicians what is important to them, so clinicians may need to provide time for them to talk and verify their understanding.
- The way a patient presents is influenced by many factors including the patient's past experience, their impression of their clinician and their perceived needs. Research evidence confirms that a clinician's attitudes and beliefs towards pain influence their patient's perceptions regarding their pain and disability; see Nijs et al. (2013) for a review. Practitioners should also consider the impact of their use of language on their patients (Stewart 2014).
- Patients appreciate clear explanations of examinations and findings before, during and after testing.
- Treatment failure may be an unavoidable step on the route to the patient's acceptance of their pain. Clinicians may have a role to play in helping their patients to understand why treatments may have not helped and whether a change in approach (for instance from treatment to management) may be appropriate.
- Patients value clinicians who talk them through examination procedures and findings before, during and after testing.
- Patients build up experience with their body and its symptoms over time. Although some prefer to abrogate responsibility, others prefer to work collaboratively with their clinician.

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