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Original Article

Patient-Defined Meaningfulness within Chronic Pain Rehabilitation: A Concept Analysis

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Abstract

Background: As the problem of chronic pain grows worldwide, rehabilitation is critical to improved patient well-being. There is thus a need for rehabilitation-focused research. It appears that outcomes are improved when patients perceive the rehabilitation process to be meaningful. However, there is no empirical evidence determining how this would be achieved. An important first step is to identify and describe the concept of meaningfulness as it is used in the chronic pain rehabilitation literature.

Objective: This paper reports the findings of a structured concept analysis to define meaningfulness from the patient perspective in chronic pain rehabilitation.

Methodology: In consultation with a medical librarian, a search strategy was developed and articles retrieved. The Walker and Avant concept analysis method was used to analyze the data, identify the defining attributes of meaningfulness, develop contrary, borderline, and model cases, and identify its antecedents and consequences.

Results: The search revealed extensive use of the terms 'meaningfulness' and 'meaningful' within the chronic pain rehabilitation literature from the healthcare provider and system perspective. However, only ten articles met the inclusion criteria, and used the terms meaningful or meaningfulness from the patients' perspective. Given the paucity of relevant studies, it was not possible to retrieve a clear definition of meaningfulness specific to the context of chronic pain rehabilitation, nor to identify specific outcome measures used to confirm whether rehabilitation is meaningful for people with chronic pain.

Conclusions: There is a worrisome gap in the chronic pain rehabilitation literature regarding the application of the concept of 'meaningfulness' as perceived by the patient. This study lays the foundation to further the conceptual clarity required for rigorous research to determine potential benefits of personally meaningful chronic pain rehabilitation. Further work is required to define and operationalize the concept, develop valid assessment tools, and build the evidence base regarding relationships between patient-defined meaningfulness and positive outcomes in rehabilitation.

Keywords: chronic pain, meaningful, rehabilitation, therapeutic encounter, therapy, engagement

Introduction

For persons with chronic pain the rehabilitation experience can be critically important. A key component of the therapeutic encounter appears

to be whether a patient finds it meaningful (Baker Silverman and MacDonald, 2015). However, what meaningfulness consists of, from the patient's perspective, is not clear. This paper

reports the findings of a concept analysis to define the construct of ‘meaningfulness’ from the patient’s perspective within the rehabilitation encounter.

Chronic pain

In recent decades chronic pain has been identified as be a significant and growing health issue (Fayaz et al. 2016). Recognized as more complex than acute pain, chronic pain is characterized by neurobiological changes accompanied by adaptations in psychological and social mechanisms (J. Katz, and Rosenbloom 2015). Changes in nervous system structure and function are self-reinforcing, and the pain experience escalates over time (Dickenson 2013; Flor 2003; Sator-Katzenschlager 2014).

Chronic pain may present, often without any detectable biological cause, as a complex and interacting pattern of physical, emotional, and cognitive pain triggers and behaviors (Flor 2003; Lumley et al. 2011; Zhuo 2014; Zhuo 2016), and is often over-represented in marginalized and disadvantaged populations (Blyth et al. 2001; Hagen et al. 2005; Henderson et al. 2013; Tunks, Crook, and Weir 2008). A large Australian study reported a prevalence of 19.1% (Henderson et al. 2013), which is similar to the prevalence reported in other industrialized parts of the world (Breivik et al. 2006; Fayaz et al. 2016). This increasing (Freburger et al. 2009) prevalence is of concern worldwide due to the impact that the condition has on individuals and society.

Chronic pain frequently results in a physical, psychological/emotional, social, occupational, and financial burden to the individual, their social support system, and society in general (Breivik et al. 2006). For example, chronic pain has been found to interfere with employment (Patel et al., 2012) and may be a factor in decisions to take early retirement or claim work disability insurance (Breivik et al. 2006).

There is often a considerable impact on daily function and quality of life (Rauf et al., 2014). Walking, carrying out normal household duties, sleep quality, mood, relationships, and overall enjoyment of life are all reported to be negatively affected (Rauf et al., 2014). This impact on quality of life, and more specifically, the activities that people value, may cause psychological distress and anxiety (Breivik et al. 2006), affect relationships (West et al. 2012), and reduce patients’ ability to carry out their usual

roles and functions within family, social, and vocational contexts (N. Katz 2002; Stewart et al. 2003; Kemler and Furnée 2002).

Given the intractable nature of chronic pain the typical focus of contemporary best practice is on managing well-being, rather than curative interventions. Contemporary management of chronic pain is positioned within a biopsychosocial framework, rather than the traditional biomedical approach which has proven to be inadequate (Gatchel et al., 2014). As this shift towards a biopsychosocial approach gains traction, research is needed to develop and test rehabilitation methods that are responsive to the psychosocial needs of patients.

Meaningfulness

There is evidence that people with chronic pain may be more engaged in their rehabilitation, and have better outcomes, when they perceive the therapy to be meaningful. A study of physical and occupational therapists in the United States found that making rehabilitation “goal oriented, meaningful and enjoyable” (Lequerica, Donnell, and Tate, 2009, pg 756) was the most beneficial strategy to engage patients in therapy.

While this one study is promising, there appears to be a paucity of research into what makes chronic pain rehabilitation meaningful. In order to develop best practice guidelines to advance this aspect of rehabilitation, further research into meaningfulness is required.

An important starting point is to define and operationalize the concept of meaningfulness from the patient’s perspective, measure its occurrence, and build the evidence base regarding the impact of meaningfulness on rehabilitation outcomes.

Research question

How is meaningfulness, from the patient perspective, conceptualised in chronic pain rehabilitation literature?

Methods

Concept Analysis

Walker and Avant (2005) provide a rigorous eight step concept analysis method to first identify the structure and function of the concept and, from this, to develop the concept’s operationalizable definition to support theory building and research. This method has been used to define person-centered care (Morgan and

Yoder 2012), client empowerment (Akpotor and Johnson, 2018), self-management (Embrey 2006), and, specifically within the chronic pain field, the concepts of pacing (Jamieson-Lega, Berry and Brown 2013) and healing (Smith, 2001). The specific steps of the method in relation to this study are detailed below.

Step 1 & 2: Select the concept and develop the aims of the analysis

The concept examined in this study was meaningfulness and the aim was to define it, from the perspective of the patient with chronic pain, as they experienced meaningfulness within the context of the rehabilitation encounter.

Step 3: Identify all uses of the concept in published literature

A search protocol, detailed in Figure 1, was developed and refined in consultation with a medical librarian. The common language use of 'meaningful' was obtained from the Oxford English Dictionary Online (Oxford English Dictionary) to assist when analyzing the articles for defining attributes.

Step 4: Define attributes of the studied concept

Eligible articles were stored in Endnote software for data analysis and all uses of the term 'meaningful' were identified. Attributes of the concept 'meaningful' that appeared frequently and consistently in the selected articles were identified as 'defining attributes'. Any uncertainty about attributes was resolved through discussion between the authors, and data analysis methods were agreed upon by authors KL and CB.

Steps 5 & 6: Identify a model case, a borderline case, and a contrary case

The defining attributes were used to construct a model case. Borderline and contrary cases, which include some or none of the attributes respectively, were developed to strengthen understanding of the concept.

Step 7: Determine the "antecedents" and "consequences"

Antecedents are those conditions that precede the concept, and consequences are the outcomes or events observed after the concept has occurred. These were determined and agreed upon by the authors.

Step 8: Determine the 'empirical referents' that indicate the presence of the concept

The literature was examined for outcome measures that would indicate 'meaningfulness' has occurred.

Results

General use of the term 'meaningful'

According to the Oxford English Dictionary (Oxford English Dictionary) the adjective 'meaningful' refers to:

1. a) Full of meaning or expression, significant; communicating something that is not explicitly or directly expressed; b) Having a serious, important, or recognizable quality or purpose.
2. Of a word, sound, etc.: conveying meaning; (Logic and Philosophy) compatible with the rules of a logical language or other sign system; able to function as a term in such a system.
3. Of data or its presentation: accurate and realistic; of practical use.

Chronic pain literature use of the term 'meaningful'

A PRISMA diagram (Figure 2) presents the findings and flow of citations (Moher et al., 2009). Though the term 'meaningful' appeared in the 113 articles that remained after exclusion criteria (Figure 1) were applied, it was not explicitly defined nor used consistently. The form most commonly used referred to 'clinical meaningfulness' which is different from the concept of interest for this study, 'patient-identified meaningfulness'. Only ten articles used the term in context of what is meaningful for the person with chronic pain, and were included in the final concept analysis.

To determine terms and limiters, a test search of two health-related electronic databases (CINAHL and MEDLINE) was first conducted. Databases used in the final search included CINAHL, MEDLINE and PsycINFO, with Embase and Google Scholar used to check for any missed items.

Search terms, using Boolean operators and truncated terms, included (chronic pain; persistent pain; ongoing pain; enduring pain; non-malignant pain; long term pain) and (rehabilitation; therapy; physical therapy; physiotherapy; occupational therapy) and (meaningful) as MeSH terms, subject headings or keywords in the title, abstract or subject heading search fields. Search limiters were English-language, peer-reviewed, not dissertations, and only those with abstract available.

Articles were excluded if they did not involve occupational therapy or physiotherapy rehabilitation interventions (for example pharmacological, surgical, medical, alternative therapies); did not focus on chronic pain (for example chronic pain was discussed secondary to another condition such as traumatic brain injury); the use of “meaningful” was in the context of the intervention or research (for example clinically meaningful change to assessment scores, rather than what is meaningful related to the patient); and if the primary topic of the article was meaning of life, or existential meaning.

Duplicate records were removed and titles and/or abstracts screened, then full text was obtained for all eligible publications. A manual search of the reference lists of included articles was conducted, and citation searching was carried out using Web of Science to check for additional publications. A final hand search of occupational therapy and physical therapy journals was conducted to insure no relevant publications were missed.

Records were kept throughout the search, and uncertainty over eligibility of publications was resolved through discussion between coauthors.

Figure 1. Detailed outline of search strategy

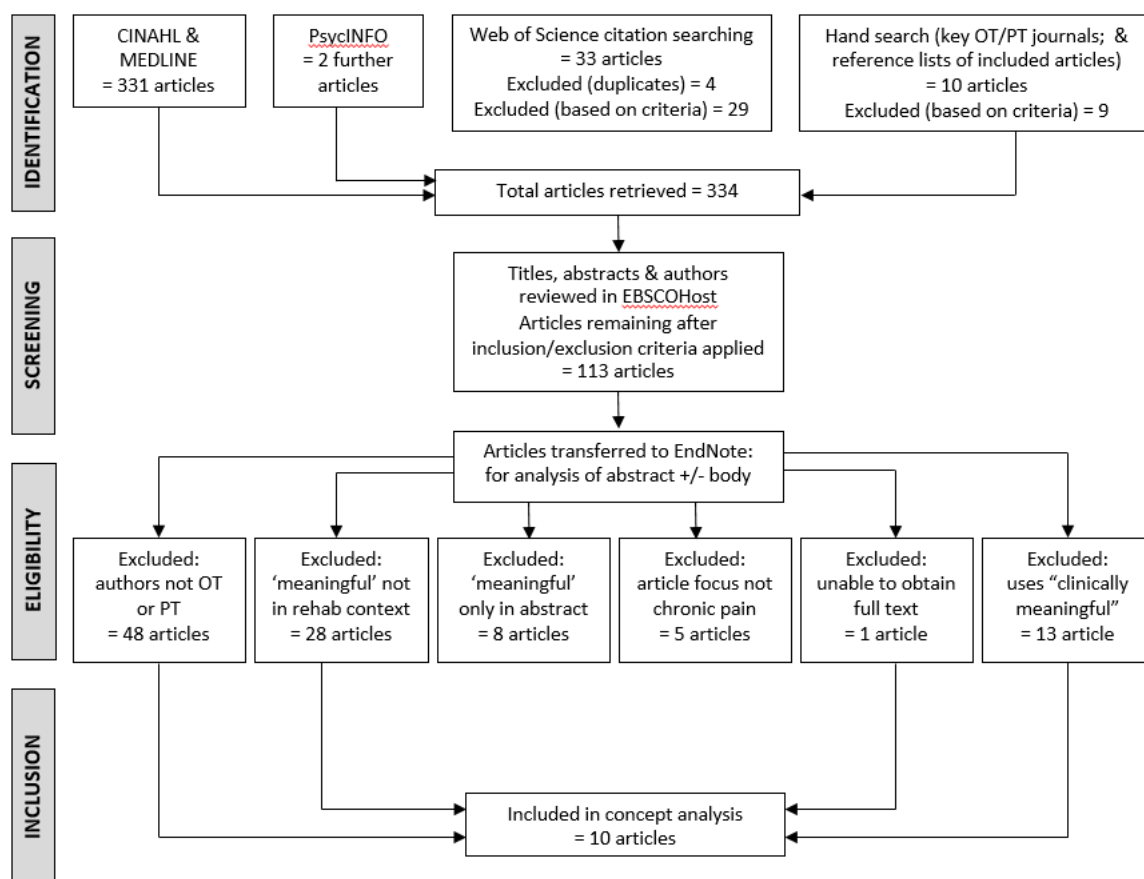


Figure 2. PRISMA diagram showing search strategy

Table 1. Attributes of “meaningfulness” identified in included articles

	Defining attribute		
	Value judgement ¹	Self-defined ²	Contributes to personal identity ³
Author (reference)			
Fuentes et al [42]	x	x	
Gardner et al [43]	x	x	
Hush et al [36]	x	x	x
Kallhed et al [37]	x	x	x
Persson D et al [38]	x	x	x
Persson E et al [44]	x	x	
Robinson et al [45]	x	x	
Sullivan et al [39]	x	x	x
Toal-Sullivan et al [40]	x	x	x
Walloch [41]	x	x	x

1. Describes something as having "meaningfulness" on the premise that the person with chronic pain judges it to be valuable, or to have meaning; 2. What has "meaningfulness" is determined by the person with chronic pain; 3. "Meaningfulness" suggests contributing to a person's sense of identity, beyond just having 'value' or being simply important, for example being closely related to a person's important life roles.

BOX 1: Contrary case

Andrea is a mother of three who has chronic shoulder pain. She enjoys being involved with her children's after school activities, often playing tennis or riding bikes along the beachfront with them. She volunteers in the crèche at her local library, and feels she has a particular ability to settle the toddlers to sleep. She has been receiving rehabilitation for her neck pain for two weeks. During that time she has seen an overall reduction in pain of around 30%. Andrea's therapist tells her this is a good outcome as it can be considered a clinically meaningful change in that time period.

BOX 2: Borderline case

Henry is a mature age university student who has had multiple knee injuries through sport. He was diagnosed with chronic pain and has seen a pain specialist for six months to help him manage medication. He was referred to a rehabilitation therapist to help him manage his pain and improve his leg muscle strength. His therapist explained to him that strengthening his leg and back muscles would be important to improve the biomechanics of his knee joint, and should help to reduce his pain.

BOX 3: Model case

Jane is a primary school teacher, who experienced a back injury when moving furniture in the classroom, and was advised to take six weeks off work. At the end of this time she was unable to return to her normal duties and had a further extended period off work, during which time she was diagnosed with chronic pain and prescribed high levels of opioids. She attended the rehabilitation clinic where the therapist asked her what impact her pain had on her daily life, and helped her to identify what she wanted to get out of her rehabilitation. Jane stated that she was frustrated about not being able to return to her role as a teacher, which she felt gave a sense of purpose to her days. She wanted her rehabilitation to help her to get back to this role. The therapist worked with Jane to help her clearly understand how specific aspects of her rehabilitation therapy match to return to work, and to establish strategies to help her achieve her goal.

Figure 3. Illustrative cases of the concept “meaningfulness” in chronic pain rehabilitation

Defining attributes of ‘meaningful’ in chronic pain rehabilitation literature

The three most consistent attributes identified in the literature were:

1. Value judgement: Describes something as ‘meaningful’ on the premise that the patient with chronic pain judges it to be valuable, or to have meaning;
2. Self-defined: What is ‘meaningful’ is determined by the patient with chronic pain rather than the therapist;
3. Contributes to personal identity: Beyond just having ‘value’ or simply being important, ‘meaningful’ suggests something which is connected to a greater purpose, for example being closely related to a person’s sense of life purpose or identity, or as the dictionary definition suggests: “communicating something that is not explicitly or directly expressed” (Oxford English Dictionary).

In six of the ten articles examined, all three attributes were apparent in the way that meaningfulness was used (Hush et al., 2010; Kallhed and Mårtensson 2018; D. Persson, Andersson, and Eklund 2011; Sullivan, Adams, and Ellis 2012; Toal-Sullivan and Henderson 2004; Walloch 1998). A further four of the articles that were examined two of the defining attributes were discussed, but these articles did not consider the third attribute (contributes to personal identity) (Fuentes et al. 2014; Gardner et al. 2015; E Persson et al. 2017; Robinson et al. 2005) (Table 1).

Model, contrary, and borderline cases were then developed using these defining attributes to clarify the concept (Figure 3). The contrary case is a clear example of what the concept is not; the borderline case contains some but not all of the defining attributes and demonstrates a similar concept; the model case contains all of the defining attributes and accurately reflects the full concept.

Contrary case

The contrary case in Box 1 (Figure 3) depicts a situation where the patient receives care deemed by the therapist to be valuable, based on clinical experience. Return of function may be influenced by a reduction in pain, but the patient is not encouraged by the therapist to decide what she values most, or identify how rehabilitation may contribute to her personal sense of identity.

Borderline case

The borderline case in Box 2 (Figure 3) is an example of an important therapeutic encounter. The therapist establishes a goal to increase muscle strength and therefore reduce pain, and both outcomes are valued by the patient, but are not self-defined. The therapist does not discuss aspects of personal identity that have been affected by the chronic pain condition.

Model case

The model case in Box 3 (Figure 3) demonstrates all three defining attributes of a meaningful therapeutic encounter: value judgment, self-defined preferences and contribution to personal identity. The therapist’s questions help the patient to become more aware of what she

values, and what contributes to her personal sense of identity.

Antecedents and consequences of 'meaningfulness'

One antecedent identified in all ten of the included articles was awareness and/or reflection. For a patient to articulate what they value, and what gives them a sense of identity, they are required to reflect or become more aware. In some cases a person may not have sufficient distance from their situation to know immediately what is meaningful for them, so the therapist may need to actively encourage this reflection.

No single clear consequence was identified in the ten included articles, however, some articles implied that patients are likely to be more engaged in personally meaningful rehabilitation.

Empirical referents that indicate 'meaningfulness' has occurred

The ten articles examined did not identify any specific chronic pain outcome measures which would indicate that 'meaningfulness', as perceived by the patient, had occurred.

Definition generation

Based on the attributes identified, the following definition of meaningfulness, in relation to chronic pain rehabilitation, is proposed:

Patient-identified meaningfulness describes that which patients themselves select as being of value, and contributes to their personal sense of identity.

Discussion

A key principle of rehabilitation is that intervention, if it is to achieve outcomes relevant to well-being, should be meaningful (Baker, Silverman and MacDonald, 2015). However, it is not yet established what makes rehabilitation meaningful for patients, or indeed how rehabilitation therapists view the concept of meaningfulness. The aim of this concept analysis was to clearly define the concept of meaningfulness from the patient's perspective. It was discovered, however, that the field of chronic pain rehabilitation lacks an agreed definition for patient-identified meaningfulness. The process of conclusively defining the concept was challenged by a) the limited literature from the chronic pain rehabilitation field that examines meaningfulness from the patient's

perspective, b) the inconsistent reference to meaningfulness, and c) the lack of a definition cited by researchers. Therefore we consider our definition (*Patient-identified meaningfulness describes that which patients themselves select as being of value, and contributes to their personal sense of identity*) as preliminary and requiring further study with the direct involvement of patients who live with pain.

Attributes of meaningfulness

The defining attributes of meaningfulness identified in the articles were 'value judgement', 'self-defined' and 'contributes to personal identity' (Table 1). The attribute 'value judgement' was mentioned in each of the selected articles. As discussed, the small body of existing research suggests that patients are more likely to consider rehabilitation encounters to be more meaningful and engaging when their own value judgement takes precedence over that of the therapist. However, meaningfulness is generally subjective, and much of what a person finds meaningful may not be immediately apparent to others (Baker, Silverman, and MacDonald 2015), or sometimes even to patients themselves. Much of the pain rehabilitation literature refers to the notion 'clinically meaningful'. For example the use of the term 'clinically meaningful pain reduction' (Day et al. 2018; Eckenrode, Kietrys, and Parrott 2018), may infer that the described amount of pain reduction is perceived by the patient to be of value. However, in this reference to meaningful it is the clinician's, not the patient's, voice that is privileged. In fact, it is not clear that patients place greater value on pain reduction in comparison to other outcomes such as being able to return to their daily activities (Hush et al. 2010). It is important for rehabilitation therapists to be aware of this distinction as it highlights the perspective and assumptions of a biomedical model, as compared to the biopsychosocial model.

The attribute 'self-defined' was also identified in all the articles (Fuentes et al. 2014; Gardner et al. 2015; Hush et al. 2010; Kallhed and Mårtensson 2018; D. Persson, Andersson, and Eklund 2011; E. Persson et al. 2017; Robinson et al. 2005; Sullivan, Adams, and Ellis 2012; Toal-Sullivan and Henderson 2004; Walloch 1998). For example, Fuentes et al. (2014) used a global rating scale to determine whether changes in response to rehabilitation were meaningful from

the participant's perspective. Researchers, outside the field of chronic pain, highlight the central place that identity, autonomy, and sense of agency hold in the experience of meaningfulness (Baker, Silverman and MacDonald 2015) and it seems reasonable to assume this would be relevant to patients with chronic pain as well. This underscores that the attribute 'self-defined' is core to the construct of meaningfulness in chronic pain rehabilitation. However, as previously identified, much of the literature focuses on clinician-defined meaningfulness (Robinson et al., 2005). Self-defined meaningfulness would appear to be an important target for research to improve outcomes in chronic pain rehabilitation.

Recent research has also established a relationship between engagement in personally meaningful goals, pain interference and a sense of well-being for people with chronic non-cancer pain (Iddon et al., 2019). We can look to other studies for inspiration on how to build the evidence-base for meaningfulness in chronic pain rehabilitation. For example, Baker and colleagues (2015) studied meaningfulness in a rehabilitation context through songwriting therapy for people with acute psychiatric disorders. As with songwriting as an expressive therapy in mental health, chronic pain rehabilitation has the potential to guide patients to reflect on what they value, and on their current and past approach to living with chronic pain.

The third attribute, 'contributes to personal identity' was contained in six of the articles (Hush et al., 2010; Kallhed and Mårtensson 2018; D. Persson, Andersson and Eklund 2011; Sullivan, Adams and Ellis 2012; Toal-Sullivan and Henderson 2004; Walloch 1998). This attribute relates closely to the cognitive dimension of meaningfulness described by Baker, Silverman & MacDonald (2015), which is concerned with "making sense of the world", "autobiographical associations" and "self-discovery" (Baker, Silverman and MacDonald 2015, p. 59). This dimension is perhaps the most challenging to capture in chronic pain rehabilitation. Steger et al. (2006) point out that the experience of meaningfulness is subjective and that individuals need to decide for themselves what gives them a sense of meaning. Toal-Sullivan and Henderson (2004) suggest that the roles that people choose or inhabit are closely linked to what they find meaningful, and the loss of role identity consequent to injury or illness

may in fact be a flag for what is personally meaningful for a patient. Chronic pain rehabilitation frequently focuses on abilities that have been lost or impaired, however, in order to achieve a meaningful rehabilitation experience, it may be equally relevant to understand the patient-valued life roles and future goals that are affected. What is important is not necessarily the same as what is meaningful. For example, for a patient with chronic low back pain, it may be *important* to address your ability to bend down and pick up objects in the workplace, however, in your role as a parent it may be *meaningful* to address your ability to play a game of soccer with your child.

Antecedents of meaningfulness

In order to experience 'meaningfulness', a person must first be aware. Awareness of self and of what one values is not a given, including for people with chronic pain. The precursors to chronic pain, such as physical, emotional, or social trauma, and also the consequences of chronic pain such as employment changes, relationship breakdown, or changes in regular activities and patterns, can all lead to a crisis in which the person questions what they value and what gives them a sense of meaning or purpose (Dickson, Knussen, and Flowers 2008). This suggests that, for a rehabilitation encounter to be meaningful, the therapist may need to help a patient explore what they currently value or find purpose in. For example one patient may value back strengthening exercises as purposeful in their own right, whereas another may only see the value in this intervention when the therapist draws a direct link between the exercises and the ability to do more of the gardening that the person values for mental well-being. The therapist who assumes the patient is already aware of this connection may miss an opportunity to integrate more meaningfulness into the rehabilitation process.

Consequences of meaningfulness

Though the selected articles did not demonstrate any consistent consequences of meaningfulness, one consequence implied by some was greater engagement on the part of the patient. For example, where the term meaningful was used to describe patient-determined goals (Toal-Sullivan and Henderson 2004), or in the context of identifying outcome measures that are personally meaningful to the patient (Hush et al. 2010), the implied consequence was greater engagement in

the rehabilitation process. Where meaningful patient activity was the focus (Kallhed and Mårtensson 2018) the implied result was greater engagement in that activity. Given that patient engagement has been linked in the literature to successful outcomes in chronic pain rehabilitation (Lotze and Moseley 2015), it is reasonable to further explore the role that meaningfulness plays in engagement as a potential target to improve rehabilitation outcomes.

Empirical referents

None of the articles included in the concept analysis provided a clear way to measure meaningfulness within chronic pain rehabilitation. This may reflect the complex and interactive nature of the concept. There is a need to identify and/or develop psychometrically strong measures that can demonstrate the occurrence of meaningfulness in chronic pain rehabilitation. Researchers in other fields have provided useful insights for this work, for example, literature describing the Meaningfulness of Songwriting Scale (Baker Silverman and MacDonald, 2015), and the Oval-PD (Eklund et al, 2009), which is based on the theory that a person must perceive value in an occupation in order to consider it meaningful (D Persson et al., 2001). These studies hold relevance for future chronic pain future research.

Conclusion

The concept 'meaningfulness' as it relates to rehabilitation for the person with chronic pain has been investigated through Walker and Avant's (2005) widely used, rigorous concept analysis method. The defining attributes 'value judgement', 'self-defined' and 'contributes to personal identity' and the antecedent 'self-awareness' were identified. Whilst much work remains to be done we propose the following definition as a basis for further theory building and testing:

Patient-identified meaningfulness describes that which patients themselves select as being of value, and relates to their personal sense of identity.

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