

PROOF COVER SHEET

Author(s): Bronwyn Lennox Thompson, Jeffrey Gage, and Ray Kirk

Article title: Living well with chronic pain: a classical grounded theory

Article no: IDRE_A_1517195

Enclosures: 1) Query sheet
2) Article proofs

Dear Author,

1. Please check these proofs carefully. It is the responsibility of the corresponding author to check these and approve or amend them. A second proof is not normally provided. Taylor & Francis cannot be held responsible for uncorrected errors, even if introduced during the production process. Once your corrections have been added to the article, it will be considered ready for publication.

Please limit changes at this stage to the correction of errors. You should not make trivial changes, improve prose style, add new material, or delete existing material at this stage. You may be charged if your corrections are excessive (we would not expect corrections to exceed 30 changes).

For detailed guidance on how to check your proofs, please paste this address into a new browser window: <http://journalauthors.tandf.co.uk/production/checkingproofs.asp>

Your PDF proof file has been enabled so that you can comment on the proof directly using Adobe Acrobat. If you wish to do this, please save the file to your hard disk first. For further information on marking corrections using Acrobat, please paste this address into a new browser window: <http://journalauthors.tandf.co.uk/production/acrobat.asp>

2. Please review the table of contributors below and confirm that the first and last names are structured correctly and that the authors are listed in the correct order of contribution. This check is to ensure that your name will appear correctly online and when the article is indexed.

Sequence	Prefix	Given name(s)	Surname	Suffix
1		Bronwyn	Lennox Thompson	
2		Jeffrey	Gage	
3		Ray	Kirk	

Queries are marked in the margins of the proofs, and you can also click the hyperlinks below.

General points:

- 1. Permissions:** You have warranted that you have secured the necessary written permission from the appropriate copyright owner for the reproduction of any text, illustration, or other material in your article. Please see <http://journalauthors.tandf.co.uk/permissions/usingThirdPartyMaterial.asp>.
- 2. Third-party content:** If there is third-party content in your article, please check that the rightsholder details for re-use are shown correctly.

3. **Affiliation:** The corresponding author is responsible for ensuring that address and email details are correct for all the co-authors. Affiliations given in the article should be the affiliation at the time the research was conducted. Please see <http://journalauthors.tandf.co.uk/preparation/writing.asp>.
4. **Funding:** Was your research for this article funded by a funding agency? If so, please insert 'This work was supported by <insert the name of the funding agency in full>', followed by the grant number in square brackets '[grant number xxxx]'.
5. **Supplemental data and underlying research materials:** Do you wish to include the location of the underlying research materials (e.g. data, samples or models) for your article? If so, please insert this sentence before the reference section: 'The underlying research materials for this article can be accessed at <full link>/ description of location [author to complete]'. If your article includes supplemental data, the link will also be provided in this paragraph. See <<http://journalauthors.tandf.co.uk/preparation/multimedia.asp>> for further explanation of supplemental data and underlying research materials.
6. The **PubMed** (<http://www.ncbi.nlm.nih.gov/pubmed>) and **CrossRef databases** (www.crossref.org/) have been used to validate the references. Changes resulting from mismatches are tracked in red font.

AUTHOR QUERIES

- Q1: Please check affiliation details as set are correct.
- Q2: Please check that the heading levels have been correctly formatted throughout.
- Q3: Please provide manufacturer detail for NVivo9 software.
- Q4: Please provide missing volume number and page numbers for [8] references list entry.
- Q5: Please provide missing volume number for [10] references list entry.
- Q6: Please provide missing publisher location for [12] references list entry.
- Q7: Please provide missing page numbers for [16] references list entry.
- Q8: Please provide missing publisher location for [18] references list entry.
- Q9: Please note, references [21] and [22] are duplicate except the initials of the author. Please check and delete if same.
- Q10: Please provide chapter title publisher and location for [36] references list entry.
- Q11: Please provide missing publisher location for [39] references list entry.
- Q12: Please provide missing volume number for [75] references list entry.
- Q13: Please provide missing volume number for [76] references list entry.
- Q14: Please provide missing publisher location for [89] references list entry.

How to make corrections to your proofs using Adobe Acrobat/Reader

Taylor & Francis offers you a choice of options to help you make corrections to your proofs. Your PDF proof file has been enabled so that you can mark up the proof directly using Adobe Acrobat/Reader. This is the simplest and best way for you to ensure that your corrections will be incorporated. If you wish to do this, please follow these instructions:

1. Save the file to your hard disk.
2. Check which version of Adobe Acrobat/Reader you have on your computer. You can do this by clicking on the Help" tab, and then About".

If Adobe Reader is not installed, you can get the latest version free from <http://get.adobe.com/reader/>.

3. If you have Adobe Acrobat/Reader 10 or a later version, click on the Comment" link at the right-hand side to view the Comments pane.

4. You can then select any text and mark it up for deletion or replacement, or insert new text as needed. Please note that these will clearly be displayed in the Comments pane and secondary annotation is not needed to draw attention to your corrections. If you need to include new sections of text, it is also possible to add a comment to the proofs. To do this, use the Sticky Note tool in the task bar. Please also see our FAQs here: <http://journalauthors.tandf.co.uk/production/index.asp>.

5. Make sure that you save the file when you close the document before uploading it to CATS using the Upload File” button on the online correction form. If you have more than one file, please zip them together and then upload the zip file. If you prefer, you can make your corrections using the CATS online correction form.

Troubleshooting

Acrobat help: <http://helpx.adobe.com/acrobat.html>

Reader help: <http://helpx.adobe.com/reader.html>

Please note that full user guides for earlier versions of these programs are available from the Adobe Help pages by clicking on the link Previous versions” under the Help and tutorials” heading from the relevant link above. Commenting functionality is available from Adobe Reader 8.0 onwards and from Adobe Acrobat 7.0 onwards.

Firefox users: Firefox's inbuilt PDF Viewer is set to the default; please see the following for instructions on how to use this and download the PDF to your hard drive: http://support.mozilla.org/en-US/kb/view-pdf-files-firefox-without-downloading-them#-w_using-a-pdf-reader-plugin

ORIGINAL ARTICLE



Living well with chronic pain: a classical grounded theory

Bronwyn Lennox Thompson^a, Jeffrey Gage^b and Ray Kirk^c

^aDepartment of Orthopaedic Surgery & Musculoskeletal Medicine, University of Otago, Christchurch, New Zealand; ^bCollege of Nursing, California Baptist University, Riverside, CA, USA; ^cUC Health, University of Canterbury, Christchurch, New Zealand

Q1

ABSTRACT

Purpose: There is little theory to explain how and why some people cope well despite chronic pain. This study proposes a mid-level theoretical explanation for those that cope well, shedding light on factors relevant to acceptance.

Method: Classical grounded theory methodology was closely followed to generate a theory grounded in data obtained from community-dwelling people self-identified as living well despite chronic pain.

Results: The main concern of people experiencing chronic pain is resolving the problem of disrupted self-coherence. Resolution involves *re-occupying self* by (1) *making sense* of pain using an idiographic model; (2) *deciding* to turn from patient to person, facilitated or hindered by interactions with clinicians and occupational drive; and (3) *flexibly persisting*, where *occupational engaging* and *coping* allow individuals to develop *future plans*.

Conclusions: This theory demonstrates the importance of engaging in occupation during rehabilitation by framing chronic pain adjustment within a process of renegotiating the self-concept. Occupations allow individuals to express values important to their sense of self. Coping strategies are used to enable occupation and are judged by their workability in this context. When developing goals and plans with people living with pain, rehabilitation professionals should consider an individual's position within the processes involved in learning to live well.

► IMPLICATION FOR REHABILITATION

- Living well with chronic pain involves a process of making sense, deciding to move on with life, and flexibly persisting.
- Diagnosis should be accompanied by messages about hurt and harm not being equivalent, and the need for a lifelong approach to managing a chronic problem.
- An idiographic depiction or formulation of a person's pain and disability provides opportunities for making sense of symptoms and collaborating on treatment goals.
- Remaining supportive, providing "small acts" demonstrating that the person is unique and being thought of, and encouraging engagement in valued occupations allows patients to experiment with, and start to engage in what is important in their lives.
- Clinicians should help people extend their coping repertoire and encourage flexibility with how these are applied in the pursuit of valued occupations.
- The positive motivation that comes from individuals identifying highly valued occupations is an aspect that all clinicians, but particularly occupational therapists, should recognize.

ARTICLE HISTORY

Received 7 December 2015

Revised 23 August 2018

Accepted 25 August 2018

KEYWORDS

Acceptance; coping; self-concept; occupation; resilience

Q2 Introduction

Chronic pain is usually viewed as distressing and disabling, yet some people cope well and do not continue seeking treatment [1]. These people are characterized by reporting little emotional distress and minimal disability while experiencing moderate to high levels of pain [2], and represent between 13% and 36% of those living with chronic pain [1,2]. There are few theories to explain resilience in persistent pain and it is thus difficult to determine whether similar strategies and processes could help those seeking treatment.

Limited information about people who cope well with chronic pain is unsurprising. High costs are associated with treating those with difficulty coping [3,4], thus, this population is prioritized for research. Locating individuals who identify as "well" for inclusion

in research studies is difficult in comparison with treatment-seeking people. Knowledge bias towards those seeking treatment means that pain management approaches target issues associated with *disability* rather than promoting *resilience*. Catastrophizing [5], depression [6,7], and exercise programs to combat physical decline [8], along with coping strategies [9,10] are usually targeted in treatment programs. While addressing these factors improves quality of life and reduces disability to a small or moderate extent [10–12], learning from people living well with chronic pain may provide new insights into effective ways of living with chronic pain.

We used classical grounded theory [13,14] to develop a mid-level explanatory theory to understand how and why some people live well with chronic pain.

Methodology and methods

Methodology

We chose Glaserian, or classical, grounded theory for this study, and readers should be aware of the distinctions between this method and other forms of grounded theory. Firstly, because it is “a-philosophical” [15], the method allows researchers to approach the data from any philosophical stance. This in contrast with constructivist grounded theory [16] which is overtly constructivist and interpretive, and the evolving but broadly post-positivist perspective of Strauss and Corbin’s version of the method [17,18]. Classical grounded theory can accommodate a broadly realist and pragmatic perspective, thus providing for theoretical relationships between variables to be tested in future studies, as well as allowing for formal theory generation across substantive domains [15,19].

In this form of grounded theory, researchers are asked to hold an independent view, separate from participants’ perspectives in what some have called a “soft positivist” perspective [20], and collect data without preconceptions drawn from existing research or theory. The data are considered to stand alone; that is, it does not require validation or “member checking” [14]. While people understand events from their own perspective and respond accordingly, latent patterns of behavior occur and can be identified by researchers hearing the same concept expressed in different ways by different participants. Consequently, the researcher is responsible for giving names to the resultant categories, drawing from concepts expressed by participants but also from existing literature.

Classical grounded theorists move from specific incidents to increasingly abstract and global concepts. Concepts emerge only after many indicators of the same pattern are identified, capturing fundamental characteristics of concepts, thus reducing the unique contribution of each individual incident and elevating the concept beyond description [19].

With this methodology, researchers aim not to produce a detailed *description* of data, but to generate integrated and related *concepts* identifying a “main concern” for participants, as well as latent patterns underlying how they continually work to resolve their main concern [14,19,21].

The credibility of the theory rests on how well the theory explains how the main concern is resolved; its fit, relevance and workability; and on ensuring rigor in following grounded theory processes [14,21]. In practical terms, this means we strictly followed the constant comparative process, saturating the categories by identifying “interchangeable indicators” found repeatedly in the data, and ensuring our coding was related to the core category or extending and qualifying the properties of each category [15,21,22]. We also did not pursue member-checking as a measure of trustworthiness, for the reasons outlined above.

Participants

Following ethical approval from the University and the New Zealand Ministry of Health ethics committees, participants were recruited to this study based on how they might contribute to the development of a theory of living well with chronic pain. Participants were initially selected on the basis that they: Self-identified as “living well” despite having chronic pain (chronic pain was defined as pain that is present for six months or more, living well was not defined to allow for a wide range of participant perspectives);

Had not attended a chronic pain management program, or seen a clinical psychologist or occupational therapist for managing their pain, to ensure participants were broadly naïve to traditional cognitive behavioral approaches for pain management; Regularly experienced moderate to severe levels of pain as measured by a visual analog scale where 0 = no pain and 10 = most severe pain.

The first few participants were recruited from Arthritis New Zealand public seminars, while purposive recruitment in the form of theoretical sampling [23] was used later to help develop the theory. Participants were also recruited via Facebook groups, the lead author’s (BLT) blog and people with rheumatological conditions featured in the media (newspaper, television and radio). Initial contact was made via email or telephone contact and participants were provided with an information sheet and consent form. Twenty-four hours after the initial communication they were contacted again to confirm participation. Participants provided signed informed consent, were advised they could withdraw at any time, and were invited to choose where the interviews were held, and if they wanted *whanau* (extended family and support people) to be present.

Participant characteristics are shown in Table 1. Seventeen people were recruited to the study with diagnoses of both rheumatological and non-rheumatological conditions. One potential participant was excluded because of prior pain management exposure while none declined involvement. Participants had been living with their pain from 12 months to over 40 years.

Participants were selected based on their ability to contribute to the emerging theory. For example, participants were initially recruited having clear-cut rheumatological diagnoses, later others were recruited with less well-defined diagnoses (e.g., comparing those with rheumatoid arthritis and those with hypermobility or fibromyalgia) and with differing rate of onset (sudden onset or insidious onset), and with varying periods before obtaining a

Table 1. Participant demographics.

Participant characteristics		%
Participants N = 17		
Age years Mean (SD)	44.53 (13.56)	
Gender Female (male)	9 (8)	53 (47)
Relationship status		
Single	6	35
De facto	3	17
Married	8	47
Dependents at home	8	47
Employment status		
Full time	17	100
Diagnosis ^a		
Rheumatoid arthritis	3	17
Psoriatic arthritis	2	11
Osteoarthritis hips, knees	4	24
Osteoarthritis hands	1	6
Fibromyalgia	3	17
Ankylosing spondylitis	2	11
Irritable bowel syndrome	1	6
Hypermobility syndrome	1	6
Juvenile arthritis	1	6
Nonspecific low back pain	1	6
Migraine	1	6
Abdominal pain	1	6
Widespread pain ?fibromyalgia	1	6
Years living with pain		
Mean (SD)	13.11 (12.19)	
Minimum	1	
Maximum	44	

^aNB percentages total more than 100 as several participants had more than one diagnosis.

definitive diagnosis. Participants' characteristics, and the questions asked during the interviews were shaped by questions arising from data already collected (as documented in memos) and gaps in the theory. Prior to making interview appointments, potential participants were asked to verify whether they could inform the questions that were currently being investigated.

Design and procedure

We aimed to generate new theoretical explanations for how and why participants believed they were living well despite their chronic pain, and for this reason we followed classical grounded theory methodology [15,19]. We prioritized the direction and prominence of concepts provided by participants by delaying an in-depth literature review until later in the analysis.

Interviews were conducted by the lead author (BLT), an experienced occupational therapist, and the study formed part of her PhD. Participants were advised of the purpose of the research, confidentiality, the clinical background of the interviewer, informed that the interview was focused on their experience and not for the purposes of treatment, and written consent was then obtained. Interviews started with the questions "How do you get on with life and live with your pain?" and "How do you do the important things you want and need to while you have chronic pain?" These questions were designed to elicit participants' main concern, while analysis aimed to identify how the main concern was resolved [22]. Subsequent questions in each interview reflected areas of the emerging theory that needed development, in an iterative and inductive process. Interviews lasted between 60 and 90 min. Two participants were re-interviewed to clarify and extend concepts relevant to the developing theory. Recruitment continued until categories were saturated, and no new properties or features of the core category were identified.

The interviews were conducted face-to-face in the person's own home where possible, or were interviewed via video conferencing, and all were audio or video recorded. Memos were written after each interview was completed, and before analysis commenced. Seven participants were interviewed with a family member present (spouse or partner) while all others were interviewed alone. Family members were advised that they should allow the participant to answer. No differences were noted between those participants interviewed with family and those interviewed alone.

Analysis

Interviews were coded by BLT more than 24 h after completion (to reduce confirmation bias) and began after the first interview, continuing throughout data collection. Interviews were played and coded within NVivo9 software. A second coder was not used because classical grounded theorists are encouraged to do their own coding to stimulate abstract conceptualization [19].

Incidents (discrete events) were identified with open codes. More than one code was assigned to each incident initially to capture as many ideas as possible, but the number of concepts were reduced with subsequent coding passes. Coding involved constant comparison, comparing data collected from different people, and data collected from people at different times to identify "interchangeable indicators that emerge [to form] a pattern" [19]. Each incident was compared with every other incident while asking: "What category does this incident indicate?"; "What property of what category does this incident indicate?"; "What is the

participant's main concern?" [14]. After the core category was saturated open coding was complete.

Selective coding was then used to code only those incidents related to the core category.

Once these categories were saturated, memos were reviewed, sorted and placed in relation to one another. Memos were used for documenting thoughts, reasoning processes and conceptual abstractions and written throughout data collection and analysis. Sorting resulted in generating theoretical codes describing the relationships between the categories. During theoretical coding and sorting existing research was incorporated into the theory. Concepts or categories were named to adequately represent the data [14,15]. Terms used to name the concept or category were derived both from participants' words and from concepts drawn from existing research [15,21]. Finally, the memos were used to enable writing up [15], resulting in a multivariate conceptual theory in which the process used by participants to resolve their main concern about living well with chronic pain is explained.

Note: Classical grounded theory is written up in conceptual terms, abstract from time, place and person rather than referring directly to the participants within the study [19,21]. For this reason, the theory below is described in present tense. All the results in this study are derived from the data obtained from participants, but because saturation was achieved, the conceptual code and consequently, the description subsumed under the code is used [19] with brief quotations used for illustration.

Findings

In this study, we found that chronic pain disrupted participants' sense of self-coherence, and their main concern was finding ways to re-occupy their sense of self. Figure 1 provides a conceptual diagram of the process of re-occupying self. Achieving self-coherence formed the core category and all other categories related to it. In the context of this study, as articulated by the participants, self-coherence is a belief that personal capabilities, motivations, goals and ways of engaging in occupations make sense. Chronic pain presents a major challenge to individuals, the way they live their lives, and their self-concept. People experiencing chronic pain must change daily habits, such as ways to clean the house, manage personal hygiene, and go to work [24,25]. Their ability to undertake the usual range of roles and social behaviors is often reduced [26,27]. Their usual ways of being and doing are challenged, resulting in the need to review beliefs and inferences about social roles and personal schema developed prior to pain onset [28]. Their sense of self-coherence is lost.

We found that returning to a sense of self-coherence consists of three sequential processes during which people living well with pain engage in the process of *re-occupying self*. Resolution involves firstly, *making sense*, developing an idiographic model of their pain; secondly, *deciding* to turn from patient to person, facilitated or hindered by interactions with clinicians and occupational drive; and finally, entering an ongoing phase of *flexibly persisting*. Having successfully completed these processes, people have achieved self-coherence.

The process of *achieving self-coherence* is about developing an understanding of the effects of pain on the way occupational demands are met, but also finding new ways of expressing important values and schemas so the changes become acceptable aspects of the self-concept.

When I began doing what matters to me, maybe in a different way but still doing them, I felt more myself again instead of this alien within my skin [female, 29, pain duration (pd) 10 years]

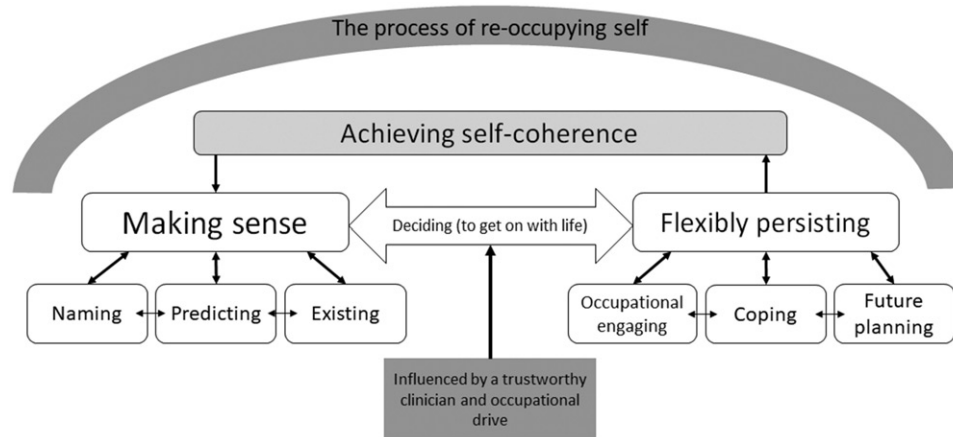


Figure 1. Conceptual diagram of the process of re-occupying self.

It didn't feel right to stop everything, I lost who I was and became this irritable, unhappy person. Getting back to the things that make me ME took a lot of time, but getting on with my cycling and work and being with my family feels right. I know who I am and pain is a small part of me. [male, 35, pd 14 years]

Occupation refers to "the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do" [29]. Occupations are imbued with personal meaning, differing from activity in that occupations are the unique and individualized way in which a person enacts a particular activity [30]. Participants were very clear about the personal relevance of the occupations they undertook, and both way they undertook them, and the purpose or values inherent in them.

Well ... you can't just stop being a mother. You have to keep doing - but I compromised how I did them and didn't feel good about that until I remembered that parents just have to be good enough, not perfect. The important thing was that I did them and that I knew why I did. In the end it's more about me doing those things that my son needs so I can still be the kind of mum I want to be. [female, 49, pd 21 years]

I didn't want to stop my sports at the time ... it was who I was, I was the guy in the front, I was the guy who got things done. I was organised and I could push myself and when I played I did it 100%. I still give it 100% and I still do my rugby because when I didn't I lost my mates, my routine, my drive. [male, 64, pd 44 years]

Phase 1: Making sense

Until chronic pain becomes a problem, most people enjoy occupations and envisage a future in which they entertain "possible selves", or "cognitive representations of enduring goals, motives, aspirations, fears, and threats" [28]. When pain persists, changes in some way (intensity, quality, association with other symptoms), or is unlike previous experiences of pain, these assumptions no longer hold true and the process of *making sense* begins. *Making sense* consists of the co-occurring processes of *naming*, *predicting* and *existing*.

The key tasks of *making sense* are to develop confidence in a personal model of pain, understanding how pain influences daily occupation and learning to self-regulate actions in light of this information (e.g., plan daily activities or integrate treatment requirements into the day). This makes engaging in occupation more predictable.

1. *Naming* involves matching information from two primary sources: their experience of symptoms, and the diagnosis made by a health provider. Information from others such as family, friends, community, social media and books or similar resources contribute to how willingly a diagnosis is accepted. Individuals continue to seek a diagnosis until they receive one matching their representation.

Once a diagnosis is made, participants in this study expressed relief using words and phrases such as "the mystery is solved", "labeled", "I knew what we were dealing with", and "now we had a direction". While the reality of living with long-term pain is not always appreciated at this time, symptoms are recognized, and energy searching for a diagnosis is diverted to learning about how symptoms vary and affect daily occupations. Validation was a term used by some participants to describe being diagnosed with "a recognized illness". The term invalidation has been used in chronic pain research to refer to a sense of disbelief from health professionals [31,32]; however, these participants indicated they felt they had been believed, but that their pain was a puzzle or a mystery until a diagnosis had been made.

2. *Predicting* is the process in which participants adjust to the reality of a body that no longer responds as expected. Activities begin to be associated with predictable changes in pain intensity. Becoming aware of these associations is an essential aspect of developing expectations in different contexts. Predicting is an experiential process, although informed by others, for example, feedback from a health professional or family member.

One participant said it like this:

I know it's only pain, I'm not doing any harm to myself, but I know what my body will and won't do. I've been living with it for so long now, I know when I'm having a flare-up and when it's just a niggle. I'll always give things a try, but in the end I'm going to do what I need to do to get things done. I mean, sometimes you just need to get on with it and decide for yourself how much you want to let it rule you, some of the things they (health professionals) want you to do for your pain get in the way more than the pain does [male, 64, pd 44 years]

3. *Existing* involves maintaining essential occupations while working through the process of *predicting*. By maintaining only essential routines, habits and tasks, individuals generate estimates about the impact of pain on performance. For example, "pain with this quality and intensity will settle down overnight", "pain that increases this fast means I need to lie down, or I'll be sick". While developing predictions,

individuals primarily focus on what they can and cannot do in the here-and-now. *Existing* is tied to the present, rather than future goals and plans. In this phase, individuals struggle to consider the future because it remains uncertain and any plans or goals are fragile.

Phase 2: Deciding

Deciding involves weighing up the costs of seeking to control pain against the rewards of (or relief of pressure to) pursuing meaningful occupations. This is an active decision to “get on with life as it is now” and occurs at a point in time rather than gradually. Timing of this decision varies, and the decision may be revisited from time-to-time with changes in symptoms or new treatments. Life “as it is now” is not an attempt to recreate the past self-concept [33], but instead focuses on engaging in valued occupations, albeit in different ways. In other words, *deciding* indicates when individuals compare their ideographic model of pain with both the cost of pursuing “return to normal” and the rewards from engaging in what is essential to their self-concept.

Deciding is influenced by what has been learned while *making sense*, including accepting that hurt does not equal harm, the relative longevity of pain, and two further factors. The first is the presence of a *trustworthy clinician*. A *trustworthy clinician* provides a sense of partnership and conveys confidence that individuals can make their own choices about treatments while continuing to remain supportive irrespective of what is chosen. Participants described clinicians conveying this attitude through small acts such as personalizing an exercise program, searching for information relevant to them, making contact in between appointments to ask how a treatment is going. The clinician may only be consulted for a short period and may be from any discipline but will always demonstrate their willingness to do “something more” and to endorse the main subsequent phase of living well: *flexibly persisting*. This elevates their clinical input beyond that of routine practice. There are parallels between the depiction of a trustworthy clinician and notions of client-centeredness as described by several authors [31,32,34], but participants used the term “trust” to depict their interactions with these clinicians, thus, we have retained this term.

We had this trust thing going on... I could decide not to do what she wanted and she'd still be there for me... and other times she'd suggest something else and I'd think about it because I knew she understood. [female, 49, pd 21 years]

It was like he trusted me to tell him how I was, what I wanted to do. [female, 45, pd 27 years]

He'd call me in between appointments, and I trusted that he really did want the best for me. [male, 55, pd 3 years]

The second influential factor when *deciding* is the strength of occupational drive. While occupational drive may be thought of as motivation, it is motivation directed towards returning to occupations the individual believes expresses who they are (i.e., important aspects of their self-concept). At this point, individuals may not fully know *how* to express their self-concept but are ready to find ways to participate in occupations irrespective of the potential for this participation to increase pain.

I looked at my life and it was these tests, pills, treatments and I realised I had nothing of me left. I'd lost myself... I really wanted to go back to my job and be me again... I needed to work for my sanity, it wasn't a want but a need [female, 42, pd 6 years]

It was like I had to get back to my sport, or what's the point? Nothing was going to stop me once I started, it's what I love. [male, 64, pd 44 years]

Phase 3: Flexibly persisting

Flexibly persisting, the third phase of living well with chronic pain, is an ongoing, lifelong process. It involves developing clarity about what is important in life, persisting with valued occupations, and being flexible when tackling challenges. Ongoing pain is accepted as a reality in life, but pain no longer holds the threat value it has while *making sense*. People in this phase are willing to experience fluctuations in pain when perceived rewards from these occupations are greater than the negative effects from increased pain or effort. Rather than managing pain, people in this phase begin to manage their lives, goals and actions.

Three processes underpin *flexibly persisting*: *occupational engaging*, *coping* and *future planning*

1. *Occupational engaging* is the process of enacting important values via participating in occupations. Occupations are “purpose in the moment” [35], and afford continuity to an individual over the course of life. They can also be described as “goal-directed activity in the context of living” [35], thus providing motivation for action as people imagine the effect of achieving these goals on their self-concept. The following quotations illustrate the importance of these occupations:

I just have to do these things: I'm a mother, there's no-one else. [female, 48, pd 7 years]

If I don't keep playing I lose something that's part of me [male, 64, pd 44 years]

What's the point if you can't do what makes you feel like yourself? [female, 45, pd 27 years]

I'm the only one who knows how to do the training, so I keep going [male, 35, pd 14 years]

Participants used daily occupations to bridge between their current self and a future state. For example, a participant said: “I *always get up and have a shower and put on my makeup, even on a bad day. I might feel like I can't handle the pain, but when I'm up and about I feel more myself.*” [female, 49, pd 21 years]. By completing her morning routine this participant confirmed that although it was “a bad day”, she could be her real self.

2. *Coping* involves all the ways people use to engage in occupation despite functional limitations, thus, ensuring their values are retained. Various strategies may be employed depending on the circumstances, and strategies are used in flexible ways. Time of the day, the day of the week, different social environments, physical environments, personal expectations and sociocultural values all influence the strategies chosen. For example, to maintain work, one participant described her coping strategies (underlined):

I plan my day. What does it matter if I ask for help, or take a nap, or rest during the day, if I can meet my client first thing in the morning because that's when I'm feeling better, then I can do that. That's why I decided to be self-employed, so I can. I will push myself to be there for a client, but crash later. Sometimes I'll decide to phone them up and change our time because it works better for me on that day. I couldn't do that if I was employed by somebody. [female, 45, pd 27 years]

Coping in this phase is conceptualized in functional and contextual terms. The utility of each coping strategy is determined by the outcome obtained in the occupational context of an individual's life. Coping *enables* occupation, while engaging in occupation *generates* the need to cope.

Coping strategies are used in a flexible way: if a strategy cannot be employed, or the situation/context means that a usual approach is unworkable, an alternative work-around is used. There were, however, three common approaches used by all participants in this study.

- i. *Mindfulness* describes the nonjudgemental awareness of pain. Individuals notice and even monitor their pain but are not bothered by it and neither ignore nor distract from it. As described by participants in this study, it involves being aware of sensations in various parts of the body, noting quality, intensity or spread, yet remaining emotionally neutral about the experience. One participant described the pain as "irrelevant", another called it "just noise", and another described being "not bothered about it, it's not important". Mindfulness as described by these participants is dispositional mindfulness or being aware of and accepting what is in the present moment, rather than using explicit mindfulness meditation practice.
- ii. *Exercise* is used in all its forms, including dance, walking, cycling, swimming, rugby, yoga. Exercising is used to maintain a "healthy body, healthy mind", maintaining fitness, and managing mood/stress. Exercise is characterized by whole body, large joint movement; most participants in the study employed more than one form and engaged in exercise daily.

One participant described it this way:

I didn't want to stop my rugby, but I thought I should because the doctor said I should be careful not to overdo things and when you play rugby you do put yourself out there. After a few years of sitting on the side-lines I decided to get back into playing again because it's who I am. If I don't keep playing I lose something that's part of me. So I started going to the gym and running so I could play rugby again, and I made the Masters team. [male, 64, pd 44 years]

Another said:

I walk a lot. It gives me 'head space' when I can let my mind wander. I always feel better in myself after it. (female, 45, pd 27 years)

- iii. *Whatever works* is a category incorporating an extensive range of strategies used to enable occupation. These include: cognitive strategies (e.g., positive self-statements, "gritting your teeth", reality testing); communication and establishing boundaries (e.g., assertive communication, asking for help, delegating); relaxation (e.g., breathing, rest, progressive muscle relaxation, differential muscle relaxation); activity management (e.g., planning, prioritizing, breaking a task into "chunks", evaluating the day/week/month's activities); passive modalities (e.g., colored light machine, osteopathy/chiropractic/physiotherapy, TENS, heat); medications (e.g., prescribed, and taken mainly in a time-contingent manner, but occasionally taken as needed); spirituality (e.g., prayer, meditation); gadgets and assistive equipment (e.g., appropriately adjusted office furniture, lumbar roll, spinner on the steering wheel).

These strategies are not used as often as mindfulness or exercise but are adopted as and when certain outcomes are desired. For example, asking for help is used to: ensure an individual can complete a valued activity; elicit caring from another; enable time-out so the person can participate in another occupation; foster interpersonal relationships; reduce fatigue or to increase

confidence. The important characteristic of these strategies is the *function* they perform for the individual *in the context* of achieving their personally valued occupations. Strategies are not, in isolation, adaptive or maladaptive, but are more or less workable in light of the purpose for which they are used. Individuals will pick and choose what is useful from any strategy they discover.

Individuals may use coping strategies to "recover" from their valued occupations so that relaxation techniques, for example, are used to help get off to sleep after being out at a function, while rest may be used after a busy day. Others plan and organize their day to achieve occupational goals, using what could be described as a "boom and bust" approach, with recovery time planned as part of an overall strategy to optimize occupational participation.

3. *Future planning* emerges as people begin to predict the nature of their symptoms and impact on their activities, use coping strategies, engage in occupation, and divert more attention to valued occupations and living life than to efforts to reduce or control their pain. In some senses, future planning is the result of pain becoming an "acceptable" experience such that energy used previously to find ways of controlling or avoiding pain can be directed towards living a purposeful life. As mentioned, during the initial process of making sense, people find it hard to plan ahead even as far as the next day, week or month. Once they have been able to make sense and have identified a repertoire of strategies that enable occupational participation, this sense of being in "limbo land" begins to fade. Future planning embodies optimism, acceptance and self-efficacy.

For a long time I didn't want to look ahead. The future wasn't a good place for me – neither was the present, but the future was so uncertain. When I began doing the things I love, my swimming, my tinkering in the shed, and found I could do these if I went about them a different way, something changed... it wasn't like I stopped wanting something to take my pain away, but I knew I didn't need that to be me. [male, 55, pd 3 years]

I don't know when I realised I was making plans again... I think... oh I think it was when I'd been doing my jewellery and began going to the craft group on a Wednesday night. I knew I might not always go – but I actually enrolled in a course for the first time in ages. [female, 35, 7 years]

I remembered that movie about the bloke with OCD, what was it... oh yeah, As good as it gets, yeah... and I thought maybe this is as good as it gets! And life isn't getting any longer. I stopped all the Dr Google searching and told my Specialist I'd had enough new drugs, and I started getting on with my life, seeing my friends on the weekends again, I even went to Australia for a holiday because I knew I could do it. [female, 42, pd 6 years]

Discussion

Living well with chronic pain, as identified in this classical grounded theory study involves *achieving self-coherence* by engaging in the process of *re-occupying self*. Individuals seek ways to express values integral to their past, present and future sense of self, and accommodate the impact of chronic pain by changing how they enact these values through daily occupations.

Self-concept

The *self* has been described as "the direct feeling each person has of privileged access to his or her own thoughts, feelings and sensations" [36]. The *self-concept* as defined by Baumeister [36] is

“the totality of inferences that a person has made about himself or herself” and incorporates an individual’s own knowledge of social roles as well as personal schemas. Lastly, Baumeister defines *identity* as “the definitions that are created for and superimposed on the self” (p. 682), consisting of an interpersonal aspect (roles and relationships), a potentiality aspect (a concept of who the person might become), and a values aspect (a set of values and priorities).

An individual’s identity develops over time through habitual preferences, emotions and thoughts towards themselves, others and the community [36,37]. Charmaz [38] maintains that habits “of thinking, feeling and action that people invoke without reflection” enable people to respond efficiently and economically, and represent a link between the self and the social world. Understanding the implications of a diagnosis on the self-concept takes both time and opportunity to explore these “habitualized notions of self”. The process of re-occupying self as described in this study illustrates how people living well with chronic pain achieve a sense of self-coherence where “habitualized notions of self” can continue to be expressed.

Self-coherence is a concept derived from Antonovsky’s sense of coherence [39]. Meaningfulness, controllability and comprehensibility are thought to contribute to an individual’s capabilities to respond to stress and are integral to the notion of sense of coherence. High sense of coherence has been found to relate to restful sleep despite stressors in elderly people [40]. In recently-diagnosed people with multiple sclerosis, sense of coherence, identity and self-efficacy were positively correlated with one another, and negatively correlated with depression, with the strongest predictors for positive affect being identity and sense of coherence [41]. In coping with pain, elderly people living with chronic illness with stronger sense of coherence were found to have lower levels of catastrophizing and reported they coped better with their pain [42], while workers with chronic pain were found to have lower levels of anxiety and higher levels of functional capability when they had a stronger sense of coherence [43].

We have used the term self-coherence to represent the sense described by participants of being able to express the deeply held values that were integral to their self-concept despite the effects of pain; of continuing to experience meaningfulness, exerting a level of control over their lives, and being able to comprehend the implications of long-term pain.

Chronic pain impacts upon all three aspects of self. Individuals with chronic pain experience a challenge to their self in the form of new sensations that in turn influence thoughts and feelings; the past self-concept may be disrupted because personal schemas cannot be enacted when pain interferes with activities, and identity may be threatened as expected roles within the community cannot be fulfilled. The future becomes less apparent, and an individual’s values may be compromised by behavioral changes required to manage pain [44].

When a person must change routines and practices, tension arises between the past self-concept and new behaviors and self-appraisals [45]. Over time, new patterns and self-appraisals eventually form a new sense of self, in response to both feedback from other people within the social context, and personal judgments about the situation, experience and interactions [28,46,47]. The self, as Charmaz argues, is continually changing, but is in particular flux during the early stages of learning to live with chronic ill health [38]. She points out that when people remain resilient despite living with disability, their bodies may change, but their “selves” remain [38].

Participants in this study experienced self-incoherence during the onset of their pain [48]. They engaged in a process of re-occupying self to establish self-coherence by modifying the range of occupations and the way they carried them out while simultaneously ensuring important values were expressed. The *need* to develop and use coping strategies emerged out of participating in important or valued daily occupations. Once they had entered the phase of flexibly persisting, their self-concept was recognizable as being “who” they were; they felt like themselves again.

In contrast with clinical populations [49,50], participants in this study were prepared to experience pain and go about doing the things they saw as important, provided that doing so helped to meet their values. During the early phases of living with persistent pain, participating in occupations provides an experiential vehicle for understanding and predicting the effects of pain on occupational performance, while later, being engaged in occupations helped participants continue to express values integral to their past, present and future sense of self.

Psychological flexibility

Those who cope well with pain appear to retain, or develop relatively quickly, a sense of self that permits a flexible approach to achieving goals. Psychological flexibility has been defined as “as the capacity to persist with or change behavior in a manner that incorporates conscious and open contact with thoughts, feelings, and sensory experiences, and in a manner that reflects one’s values and goals [51,52], and can be summarized as being able to “show up, let go and get moving” [53]. Psychological flexibility and sense of self has been discussed, with particular attention paid to psychological inflexibility [54]. In a recent review of the construct of self from within a functional contextual perspective [28], the authors argue that adopting a psychological flexibility model would encouraged people to view themselves with compassion, stepping back from value judgments about characteristics they define and instead seeing that they exist irrespective of what they can and cannot do [28,55]. Participants in this study appear to have implemented this approach naturally and without coaching, being able to step back from previously held self-evaluations, supporting their efforts to integrate the impact of chronic pain while retaining or rebuilding an intact sense of self [55]. Having achieved this, they accepted their situation – and achieved self-coherence.

Processes

The three processes involved in achieving self-coherence describe a process in which individuals move towards accepting chronic pain. The process of *making sense* involves developing an ideographic model of pain and understanding the implications of chronic pain on the self-concept. *Deciding* depicts the moment when individuals choose to move on with life, while *flexibly persisting* is the ongoing process of living with chronic pain.

Clinicians working with people experiencing pain will likely mostly encounter people working through the process of *making sense*. The concept of a period in which people begin to discover the impact of a diagnosis has appeared in other research exploring the meaning of chronic pain [48,56,57], however, the sub-processes do not appear to have been depicted in occupational terms.

The three sub-processes involved in *making sense* help define the extent and duration of the changes required and an understanding of the “new normal” while maintaining only those

occupations necessary for day-to-day living. During this period, individuals explore the impact of symptoms on their daily lives while being unable to develop plans for a (now) uncertain future. The limitations on future planning explain some of the reluctance to set goals experienced by people living with chronic pain [33,58]. It is difficult for people to generate future goals while the current situation remains poorly defined.

Naming poses particular problems for those who may ultimately be diagnosed with “contested” disorders such as fibromyalgia, or who receive diagnoses that take some time to obtain such as ankylosing spondylitis [59,60] because of delays in diagnosis, while the actions of clinicians can impact on the time needed to complete this phase. Participants in this study indicated that naming involved clinicians recognizing the condition and indicating that it was unlikely to be cured but would require ongoing management – and that management options were known. Clinicians were clear that “hurt does not equal harm” and that it was safe to be active even though pain was present. Interestingly, the stigma of having an unexplained pain problem did not emerge as a category, rather, the “mysterious” nature of their pain problem, and the desire for clarity around management emerged more strongly.

Several researchers have found that individuals are helped by being provided with a clear diagnosis and indication of chronicity [48,58] while providing people with clear information about pain mechanisms has been shown to benefit people with chronic pain because this ensures clarity around the risk of tissue damage while pain is present [61,62].

Delays in diagnosis, particularly where imaging or laboratory results are not definitive have been found to impact upon stress experienced by people [63], delay appropriate management [64], engender stigma and disbelief amongst health professionals [65], and contribute to discrepancies in the goals of chronic pain management between clinicians and patients [66].

Predicting is the process of defining symptom variability and impact on activity tolerance. It may be facilitated by recording pain intensity, location and quality, and the fluctuations that occur over time. Pain diaries have been used to establish pain variability [67], but appear less often in the literature over recent years although electronic applications on smartphones are very popular. There is some concern that individuals unnecessarily monitor symptoms and therefore become distressed or feel helpless, particularly if they score highly on measures of catastrophizing [68,69]. Several early studies indicated that becoming aware of and monitoring pain fluctuations is often described as a strategy by those living with pain, but this has not recently been investigated in-depth [70,71]. Participants in this study used their daily occupations as a vehicle by which they could identify and predict the impact of symptoms, suggesting that pain diaries should incorporate activity recordings alongside pain and other symptom ratings to enhance this part of making the sense process. When combined with a clear understanding that pain does not inevitably represent tissue damage, developing an awareness of relationships between symptoms and daily occupations may provide insights into how daily routines and habits can be structured to optimize valued occupations.

Existing is the third sub-process in this first phase of living well. It represents the lack of future focus experienced by people as they work through sub-processes of naming and predicting while making sense of their situation. Remaining focused on the here and now is well-described in chronic pain research [72,73], but may not be reflected in rehabilitation professionals’ attempts

to set goals [74] unless they adhere strongly to client/patient-centered practice [72,75,76].

Deciding

Deciding when to move on with life is a critical point in the process of living well with chronic pain. As noted above, the timing of this decision is influenced by the actions of clinicians involved in their care as well as the person’s occupational drive.

Most of the research into coping and chronic pain has investigated people experiencing pain rather than the actions of their treatment providers. Recent studies have found that the ways clinicians interact with their patients is highly influential. Clinicians with fear-avoidant beliefs about pain tend to be less inclined to support activity and more likely to recommend rest, medication and investigations [77,78], while the model of pain held by clinicians influences how much emphasis they place on psychosocial factors [79].

Several aspects of clinician’s behavior influenced the process of deciding. Clinicians’ willingness to collaborate or work in partnership with participants and individualize their input with personal touches facilitated this decision. Patient-centered care research has generated an increasing focus on ways clinicians can create a “conditional partnership” where patients are believed, encouraged and their personal journey toward wellbeing is supported [31]. In this study, clinicians who maintained a focus on pain reduction, offered new investigations or ongoing interventions, or suggested restricting activities, served to prolong the period of making sense. Clinicians who tailor their approach to the individual needs and preferences of people with pain have an impact on clinical outcomes, and this may be an important aspect of clinical communication to examine in more detail [31,34,80]. Clinicians who focus exclusively on pain reduction and investigations or treatment have been found to prolong disability [81], and this may be particularly relevant for people who have relative inflexibility in how they approach occupation, or who struggle to find ways to express their sense of self.

Flexibly persisting

Flexibly persisting explicates two important factors in living well with chronic pain: the first is the importance of identifying and participating in valued occupations or “doing everyday things” that express fundamental beliefs about the self-concept [82]; while the second highlights the benefits of knowing and applying a range of coping strategies to enable participation.

Identifying valued occupations and why they are important provides a framework for clinicians to help individuals to develop coping strategies, particularly when reducing pain intensity is not possible. Motivation to learn and adopt coping strategies only makes sense when viewed in terms of how the strategies enable participation.

Study participants used coping strategies to ensure valued occupational goals were met rather than simply to reduce pain. They described flexibility in the way they used their strategies. That is, they did not apply rigid thoughts, rules, or beliefs that made it difficult to use a range of approaches [83]. Coping strategies were adopted on the pragmatic basis of workability; the choice of which strategy to use and the impact on pain intensity varied with context and purpose. This flexible approach reflects a contextual view of coping strategies, in contrast to classical views of coping as either active or passive [84,85].

Coping inventories omit reference to contextual factors such as the purpose or end goal intended from using a strategy; individual values; time since pain onset; available resources or employment/workplace factors [86,87]. From our study it appears that coping strategies cannot be considered separately from the contexts and outcomes in which they are employed. This may mean clinicians' attitudes and understanding of various coping strategies may need to be revisited. We argue that a functional contextual perspective [88] may offer a pragmatic approach to understanding the way individuals use coping strategies. From this position, coping behavior is judged in terms of how well the strategies enable the individual to participate in valued occupations [89]. In other words, when attempting to determine if a coping strategy should be encouraged, clinicians need to consider how well it helps the person live the life they want to lead [87,90,91].

Taken together, these findings suggest steps that clinicians can take to reduce the time spent in the process of *making sense* and *deciding*, ultimately helping people move towards *flexibly persisting* more quickly.

Study limitations

Classical grounded theory is a flexible and robust methodology for exploring complex processes to generate new explanations or hypotheses. While there is considerable support for the approach, the usual limitations of data obtained by self-report and interview apply.

Participants had some difficulty recalling the coping strategies they used. They instead remarked that they "just got on with it" or "it had to be done, so I did it". A range of questions were used to probe descriptions, such as anchoring recall to recent events, asking about typical ways of coping, enquiring about "important" events. In future studies, exploring the contextual use of coping strategies in daily life by using ambulatory monitoring, experience sampling or ecological momentary assessment methods [92] would provide greater insight into choices about using coping strategies in different settings and for what purpose.

Classical grounded theory generates substantive theory; that is, a theory located in time, space and context. This research was conducted in New Zealand during disruption after several major earthquakes; this is ongoing today. Some participants were coping with not only their chronic pain, but also disruption to property and lifestyle. These events may have influenced participants' choice to respond, and the ways in which they did. Coping with the earthquakes did not feature as a concept in this study, suggesting that participants recruited from the affected area did not view this disruption as relevant to their experience of living well with chronic pain.

Classical grounded theorists do not test hypotheses emerging from data, with Glaser differentiating between his original approach and other forms of grounded theory [15], thus, further hypothesis testing derived from the theory should be conducted before strong recommendations are made regarding clinical practice.

Conclusions and recommendations

Self-management strategies for chronic pain are likely to be needed for many years because progress towards an effective pharmacological or medical approach is slow [93]. By studying people who believe they are living well with persistent pain, particularly, those who are naïve to cognitive behavioral approaches

to self-management, clinicians and researchers can begin to understand ways they can support positive adjustment to this ongoing problem.

The study explains how individuals accept chronic pain as part of their life. Processes used by these participants offer opportunities for therapeutic intervention, building on strengths already being employed in the adjustment process. The findings identify that attention should be paid not only to individuals with chronic pain and the ways they manage, but also to clinician's behaviors.

Clinicians play an important part in helping people through the processes of making sense, deciding and ultimately, flexibly persisting. Firstly, they can provide a diagnosis that fits with the person's representation of their pain problem. Participants in our study indicated that by presenting management as a "known", the unknown nature of the disease involved was mysterious rather than frightening. This action should be accompanied by messages about hurt and harm not being equivalent, and the need for a lifelong approach to managing a chronic problem. Doing so, enables patients to begin experimenting with predicting the impact of pain on what they want to do.

Secondly, clinicians can guide patients to track the impact of pain on current daily occupational performance; to begin a process of developing predictions while patients are temporarily unable to envisage a future. This may mean returning to approaches that have been relatively under-used such as pain diaries where pain and other symptoms can be recorded against daily occupations.

During the process of making sense, clinicians should aim to help patients generate an idiographic depiction or formulation of their pain. This formulation can then be used to identify mechanisms underpinning disability associated with pain and facilitate a collaborative approach to treatment and goal-setting. Goals set too far in the future should be avoided.

The process of deciding is underpinned by clinicians strongly supporting patient-centered actions, even when this does not fit with existing evidence. Remaining supportive, providing "small acts" demonstrating that the person is unique and being thought of, an encouraging engagement in valued occupations allows patients to experiment with, and start to engage in what is important in their lives.

Finally, clinicians should help people extend their coping repertoire, and encourage flexibility with how these are applied in the pursuit of valued occupations. The positive motivation that comes from individuals identifying highly valued occupations is an aspect that all clinicians, but particularly occupational therapists, should recognize. Occupations allow individuals to enact important values while satisfying the need to live a life aligned with what is personally important, and successful participation in occupations affords greater quality of life for those with chronic pain.

Acknowledgments

The authors wish to acknowledge the contributions of all participants to this study, particularly considering the disruption to their lives during the Christchurch earthquakes.

Disclosure statement

No potential conflict of interest was reported by the authors.

References

- 1135
1136
1137
1138
1139
1140
1141
1142
1143
1144
1145
1146
1147
1148
1149
1150
1151
1152
1153
1154
1155
1156
1157
1158
1159
1160
1161
1162
1163
1164
1165
1166
1167
1168
1169
1170
1171
1172
1173
1174
1175
1176
1177
1178
1179
1180
1181
1182
1183
1184
1185
1186
1187
1188
1189
1190
1191
1192
1193
1194
1195
1196
1197
- Q4
Q5
Q6
Q7
Q8
- [1] Dominick C, Blyth F, Nicholas M. Patterns of chronic pain in the New Zealand population. *N Z Med J*. 2011;124:63–76.
- [2] Karoly P, Ruehlman LS. Psychological “resilience” and its correlates in chronic pain: findings from a national community sample. *Pain* 2006;123:90–97.
- [3] Raftery MN, Ryan P, Normand C. The economic cost of chronic noncancer pain in Ireland: results from the PRIME study, part 2. *J Pain*. 2012;13:139–145.
- [4] Leadley RM, Armstrong N, Lee YC, et al. Chronic diseases in the European Union: the prevalence and health cost implications of chronic pain. *J Pain Palliat Care Pharmacother*. 2012;26:310–325.
- [5] Sullivan MJLP, Adams H, Ellis T. Targeting catastrophic thinking to promote return to work in individuals with fibromyalgia. *J Cogn Psychother*. 2012;26:130–142.
- [6] Ramírez-Maestre C, Esteve R, López AE. The role of optimism and pessimism in chronic pain patients adjustment. *Span J Psychol*. 2012;15:286–294.
- [7] Nicholas MK, Asghari A, Corbett M, et al. Is adherence to pain self-management strategies associated with improved pain, depression and disability in those with disabling chronic pain? *Eur J Pain*. 2012;16:93–104.
- [8] Geneen LJ, Moore A, Clarke C, et al. Physical activity and exercise for chronic pain in adults: an overview of Cochrane Reviews. *Cochrane Database Syst Rev*. 2017;??:??.
- [9] Roditi D, Waxenberg L, Robinson ME. Frequency and perceived effectiveness of coping define important subgroups of patients with chronic pain. *Clin J Pain*. 2010;26:1–682.
- [10] Björnsdóttir SV, Triebel J, Arnjótósdóttir M, et al. Long-lasting improvements in health-related quality of life among women with chronic pain, following multidisciplinary rehabilitation. *Disabil Rehabil*. 2017;??:1–9.
- [11] Oliver S, Fisher K, Childs S. What psychological and physical changes predict patients’ attainment of personally meaningful goals six months following a CBT based pain management intervention? *Disabil Rehabil*. 2017;39:2308–2314.
- [12] McJunkin T, Swing E, Walters K, et al. Multidisciplinary pain management in the rehabilitation patient. *Comprehensive pain management in the rehabilitation patient*. ??: Springer; 2017; p. 13–21.
- [13] Glaser B. The constant comparative method of qualitative analysis. *Social Problems*. 1965;12:436–445.
- [14] Glaser B. *Doing grounded theory: issues and discussions*. Mill Valley, CA: Sociology Press; 1998.
- [15] Glaser B. *The grounded theory perspective III: theoretical coding*. Mill Valley, CA: Sociology Press; 2005.
- [16] Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. In: Silverman D, editor. *Introducing qualitative methods*. London: Sage Publications; 2006. p. ??.
- [17] Strauss A, Corbin J. *Grounded theory methodology*. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research*. Thousand Oaks, CA: Sage; 1994. p. 273–285.
- [18] Strauss A, Corbin JM. *Grounded theory in practice*. ??: Sage Publications, Incorporated; 1997.
- [19] Glaser B. *Getting out of the data: grounded theory conceptualization*. Mill Valley, CA: Sociology Press; 2011.
- [20] Kenny M, Fourie R. Contrasting classic, Straussian, and Constructivist grounded theory: Methodological and philosophical conflicts. *Qual Rep*. 2015;20:1270–1289.
- [21] Glaser B. *The grounded theory perspective: conceptualization contrasted with description*. Mill Valley, CA: Sociology Press; 2001.
- [22] Glaser BG. *The grounded theory perspective: conceptualisation contrasted with description*. Mill Valley, CA: Sociology Press; 2001.
- [23] Glaser B. *The grounded theory perspective II: Descriptions remodeling of grounded theory methodology*. Mill Valley, CA: Sociology Press; 2003.
- [24] Stenberg G, Fjellman-Wiklund A, Ahlgren C. ‘I am afraid to make the damage worse’ - fear of engaging in physical activity among patients with neck or back pain – a gender perspective. *Scand J Caring Sci*. 2014;28:146–154.
- [25] Inoue S, Taguchi T, Yamashita T, et al. The prevalence and impact of chronic neuropathic pain on daily and social life: a nationwide study in a Japanese population. *Eur J Pain*. 2017;21:727–737.
- [26] McKillop AB, Carroll LJ, Dick BD, et al. Measuring participation in patients with chronic back pain—the 5-Item Pain Disability Index. *Spine J*. 2018;18:307–313.
- [27] Buragadda S, Aleisa ES, Melam GR. Fear avoidance beliefs and disability among women with low back pain. *Neuropsychiatry (London)*. 2018;8:80–86.
- [28] Yu L, Norton S, Harrison A, et al. In search of the person in pain: a systematic review of conceptualization, assessment methods, and evidence for self and identity in chronic pain. *J Context Behav Sci*. 2015;4:246–262.
- [29] WFOT. Definition “occupation” [Web page]. Australia: WFOT Secretariat; 2010 [updated 2011; cited 2013 Sep 05]; In occupational therapy, occupations refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do.]. Available from: <http://www.wfot.org/aboutus/aboutoccupationaltherapy/definitionofoccupationaltherapy.aspx>
- [30] Pierce D. Untangling occupation and activity. *Am J Occup Ther*. 2001;55:138–146.
- [31] Howarth M, Warne T, Haigh C. Pain from the inside: understanding the theoretical underpinning of person-centered care delivered by pain teams. *Pain Manage Nurs*. 2014;15:340–348.
- [32] Lehti A, Fjellman-Wiklund A, Stalnacke B-M, et al. Walking down ‘Via Dolorosa’ from primary health care to the specialty pain clinic—Patient and professional perceptions of inequity in rehabilitation of chronic pain. *Scand J Caring Sci*. 2017;31:45–53.
- [33] Hellstrom C. Temporal dimensions of the self-concept: entrapped and possible selves in chronic pain. *Psychol Health*. 2001;16:111–124. doi: <http://dx.doi.org/10.1080/08870440108405493>.
- [34] Gardner T, Refshauge K, McAuley J, et al. Patient-led goal setting: a pilot study investigating a promising approach for the management of chronic low back pain. *Spine*. 2016; 41:1405–1413.
- [35] Christiansen CH. Defining lives: occupation as identity: an essay on competence, coherence, and the creation of meaning. *Brit J Occup Ther*. 1999;53:547–558.
- [36] Baumeister RF. Identity, self-concept, and self-esteem: the self lost and found. Hogan, Robert [Ed]. ??: 1997; ??:681–710.
- 1198
1199
1200
1201
1202
1203
1204
1205
1206
1207
1208
1209
1210
1211
1212
1213
1214
1215
1216
1217
1218
1219
1220
1221
1222
1223
1224
1225
1226
1227
1228
1229
1230
1231
1232
1233
1234
1235
1236
1237
1238
1239
1240
1241
1242
1243
1244
1245
1246
1247
1248
1249
1250
1251
1252
1253
1254
1255
1256
1257
1258
1259
1260
- Q9
Q10

- 1261 [37] Christiansen C. Identity, personal projects and happiness: self construction in everyday action. *J Occup Sci.* 2000;7: 1262 98–107. 1263
- 1264 [38] Charmaz K. The self as habit: the reconstruction of self in 1265 chronic illness. *Occup Ther J Res.* 2002;22:315–415. 1266
- 1267 [39] Antonovsky A. *Unraveling the mystery of health: how people 1268 manage stress and stay well. ??: Jossey-bass; 1987.* 1269
- 1270 [40] Teraoka S, Hayashida N, Shinkawa T, et al. Good stress 1271 management capability is associated with lower body mass 1272 index and restful sleep in the elderly. *Tohoku J Exp Med.* 1273 2013;229:5–10. 1274
- 1275 [41] Calandri E, Graziano F, Borghi M, et al. Depression, positive 1276 and negative affect, optimism and health-related quality of 1277 life in recently diagnosed multiple sclerosis patients: the 1278 role of identity, sense of coherence, and self-efficacy. *J 1279 Happiness Stud.* 2018;19:277–295. 1280
- 1281 [42] Andruszkiewicz A, Basińska MA, Felsmann M, et al. The 1282 determinants of coping with pain in chronically ill geriatric 1283 patients – the role of a sense of coherence. *Clin Interv 1284 Aging.* 2017;12:315. 1285
- 1286 [43] Lillefjell M, Jakobsen K, Ernstsens L. The impact of a sense 1287 of coherence in employees with chronic pain. *Work.* 2015; 1288 50:313–322. 1289
- 1290 [44] Soklaridis S, Cartmill C, Cassidy D. Biographical disruption 1291 of injured workers in chronic pain. *Disabil Rehabil.* 2011;33: 1292 2372–2380. 1293
- 1294 [45] Higgins ET. Value from regulatory fit. *Curr Dir Psychol Sci.* 1295 2005;14:209–213. 1296
- 1297 [46] Bremander A, Bergman S, Arvidsson B. Perception of multi- 1298 modal cognitive treatment for people with chronic wide- 1299 spread pain—changing one's life plan. *Disabil Rehabil.* 2009; 1300 31:1996–2004. 1301
- 1302 [47] Kuhl J, Quirin M, Koole SL. Being someone: the integrated 1303 self as a neuropsychological system. *Social Personality 1304 Psychol Compass.* 2015;9:115–132. 1305
- 1306 [48] Gullacksen AC, Lidbeck J. The life adjustment process in 1307 chronic pain: psychosocial assessment and clinical implica- 1308 tions. *Pain Res Manage.* 2004;9:145–153. 1309
- 1310 [49] Goldberg P, Zepplier G, Bialosky J, et al. Kinesiophobia and 1311 its association with health-related quality of life across 1312 injury locations. *Arch Phys Med Rehabil.* 2018;99:43–48. 1313
- 1314 [50] Shim E-J, Hahm B-J, Go DJ, et al. Modeling quality of life in 1315 patients with rheumatic diseases: the role of pain cata- 1316 strophizing, fear-avoidance beliefs, physical disability, and 1317 depression. *Disabil Rehabil.* 2018;40:1509–1516. 1318
- 1319 [51] Scott W, Hann KEJ, McCracken LM. A comprehensive exam- 1320 ination of changes in psychological flexibility following 1321 acceptance and commitment therapy for chronic pain. *J 1322 Contemp Psychother.* 2016;46:139–148. 1323
- 1324 [52] McCracken LM, Morley S. Reply to Johan W. S. Vlaeyen and 1325 to Melissa A. Day and Beverly E. Thorn. *J Pain.* 2014;15: 1326 239–240. 1327
- 1328 [53] Hayes SC, Levin ME, Plumb-Villardaga J, et al. Acceptance 1329 and commitment therapy and contextual behavioral sci- 1330 ence: examining the progress of a distinctive model of 1331 behavioral and cognitive therapy. *Behav Ther.* 2013;44: 1332 180–198. 1333
- 1334 [54] Kwok SSW, Chan ECC, Chen PP, et al. The "self" in pain: the 1335 role of psychological inflexibility in chronic pain adjust- 1336 ment. *J Behav Med.* 2016;39:908–915. 1337
- 1338 [55] Yu L, McCracken LM. Model and processes of acceptance 1339 and commitment therapy (ACT) for chronic pain including 1340 a closer look at the self. *Curr Pain Headache Rep.* 2016;20: 1341 12. 1342
- 1343 [56] Hagger MS, Orbell S. A meta-analytic review of the com- 1344 mon-sense model of illness representations. *Psychol Health.* 1345 2003;18:141–184. 1346
- 1347 [57] Leventhal H, Phillips LA, Burns E. The common-sense model 1348 of self-regulation (CSM): a dynamic framework for under- 1349 standing illness self-management. *J Behav Med.* 2016;39: 1350 935–946. 1351
- 1352 [58] Hellstrom C. Affecting the future: chronic pain and per- 1353 ceived agency in a clinical setting. *Time Soc.* 2001;10: 1354 77–92. 1355
- 1356 [59] Mengshoel AM, Mengshoel AM. Living with a fluctuating 1357 illness of ankylosing spondylitis: a qualitative study. 1358 *Arthritis Rheum.* 2008;59:1439–1444. 1359
- 1360 [60] Salvadorini G, Bandinelli F, Delle Sedie A, et al. Ankylosing 1361 spondylitis: how diagnostic and therapeutic delay have 1362 changed over the last six decades. *Clin Exp Rheumatol.* 1363 2012;30:561–565. 1364
- 1365 [61] Louw A, Diener I, Butler DS, et al. The effect of neurosci- 1366 ence education on pain, disability, anxiety, and stress in 1367 chronic musculoskeletal pain. *Arch Phys Med Rehabil.* 2011; 1368 92:2041–2056. 1369
- 1370 [62] Louw A, Puentedura EL, Mintken P. Use of an abbreviated 1371 neuroscience education approach in the treatment of 1372 chronic low back pain: a case report. *Physiother Theory 1373 Pract.* 2012;28:50–62. 1374
- 1375 [63] Rice DB, Mehta S, Serrato J, et al. Stress in patients diag- 1376 nosed with rheumatoid arthritis compared to chronic pain. 1377 *Rehabil Psychol.* 2017;62:571–579. 1378
- 1379 [64] Braun J, Sieper J. Classification, diagnosis, and referral of 1380 patients with axial spondyloarthritis. *Rheum Dis Clin North 1381 Am.* 2012;38:477–485. 1382
- 1383 [65] Betsch TA, Gorodzinsky AY, Finley G, et al. What's in a 1384 name? Health care providers' perceptions of pediatric pain 1385 patients based on diagnostic labels. *Clin J Pain.* 2017;33: 1386 694–698. 1387
- 1388 [66] Henry SG, Bell RA, Fenton JJ, et al. Goals of chronic pain 1389 management: Do patients and primary care physicians 1390 agree and does it matter? *Clin J Pain.* 2017;33:955–961. 1391
- 1392 [67] Clarke K, Iphofen R. Issues in phenomenological nursing 1393 research: the combined use of pain diaries and interview- 1394 ing. *Nurse Res.* 2006;13:62–74. 1395
- 1396 [68] Lefebvre JC, Keefe FJ. Memory for pain: the relationship of 1397 pain catastrophizing to the recall of daily rheumatoid arth- 1398 ritis pain. *Clin J Pain.* 2002;18:56–63. 1399
- 1400 [69] White PD, Goldsmith KA, Johnson AL, et al. Comparison of 1401 adaptive pacing therapy, cognitive behaviour therapy, 1402 graded exercise therapy, and specialist medical care for 1403 chronic fatigue syndrome (PACE): a randomised trial. 1404 *Lancet.* 2011;377:823–836. 1405
- 1406 [70] Strong J, Large R. Coping with chronic low back pain: an 1407 idiographic exploration through focus groups. *Int J 1408 Psychiatry Med.* 1995;25:371–387. 1409
- 1410 [71] Beaton CA. *Understanding the process of pain manage- 1411 ment among male veterans with seropositive rheumatoid 1412 arthritis.* Los Angeles, CA: University of California; 2008. 1413
- 1414 [72] Souza PP, Salata Romão A, Rosa-e-Silva JC, et al. Qualitative 1415 research as the basis for a biopsychosocial approach to 1416 women with chronic pelvic pain. *J Psychosom Obstetr 1417 Gynecol.* 2011;32:165–172. 1418

- 1387 [73] Skuladottir H, Halldorsdottir S. The quest for well-being:
1388 self-identified needs of women in chronic pain. *Scand J*
1389 *Caring Sci.* 2011;25:81–91.
- 1390 [74] Arvinen-Barrow M. Back to basics: using goal setting to
1391 enhance rehabilitation. *Sportex Med.* 2008;37:15–19.
- 1392 [75] Gardner T, Refshauge K, McAuley J, et al. Goal setting prac-
1393 tice in chronic low back pain. What is current practice and
1394 is it affected by beliefs and attitudes? *Physiother Theory*
1395 *Pract.* 2018;?:1–11.
- 1396 [76] Alanko T, Karhula M, Kröger T, et al. Rehabilitees perspec-
1397 tive on goal setting in rehabilitation – a phenomenological
1398 *approach.* *Disabil Rehabil.* 2018;?:1–9.
- 1399 [77] Berquin A, Grisart J. To prescribe or not to prescribe... (in
1400 chronic pain... and elsewhere...)? *Ann Phys Rehabil Med.*
1401 2011;54:465–477.
- 1402 [78] Darlow B, Dowell A, Baxter GD, et al. The enduring impact
1403 of what clinicians say to people with low back pain. *Ann*
1404 *Family Med.* 2013;11:527–534.
- 1405 [79] Pincus TP, Kent PP, Bronfort GP, et al. Twenty-five years
1406 with the biopsychosocial model of low back pain-is it time
1407 to celebrate? A report from the twelfth international forum
1408 for primary care research on low back pain. *Spine.* 2013;38:
1409 2118–2123.
- 1410 [80] Kerns RD, Burns JW, Shulman M, et al. Can we improve
1411 cognitive-behavioral therapy for chronic back pain treat-
1412 ment engagement and adherence? A controlled trial of tail-
1413 ored versus standard therapy. *Health Psychol.* 2014;33:
1414 938–947.
- 1415 [81] Maher C, Underwood M, Buchbinder R. Non-specific low
1416 back pain. *Lancet.* 2017;389:736–747.
- 1417 [82] van Huet H, Innes E, Whiteford G. Living and doing with
1418 chronic pain: narratives of pain program participants. *Disabil*
1419 *Rehabil.* 2009;31:2031–2040.
- 1420 [83] Wicksell RK, Renöfält J, Olsson GL, et al. Avoidance and
1421 cognitive fusion—Central components in pain related
1422 disability? Development and preliminary validation of the
1423 Psychological Inflexibility in Pain Scale (PIPS). *Eur J Pain.*
1424 2008;12:491–500.
- 1425 [84] Mercado AC, Carroll LJ, Cassidy J, et al. Passive coping is a
1426 risk factor for disabling neck or low back pain. *Pain.* 2005;
1427 117:51–57.
- 1428 [85] Carroll LJ, Ferrari R, Cassidy JD, et al. Coping and recovery
1429 in whiplash-associated disorders: early use of passive cop-
1430 ing strategies is associated with slower recovery of neck
1431 pain and pain-related disability. *Clin J Pain.* 2014;30:1–8.
- 1432 [86] Day MA, Thorn BE, Burns JW. The continuing evolution of
1433 biopsychosocial interventions for chronic pain. *J Cogn*
1434 *Psychother.* 2012;26:114–129.
- 1435 [87] Litt MD, Tennen H. What are the most effective coping
1436 strategies for managing chronic pain? *Pain Manag.* 2015;5:
1437 403–406.
- 1438 [88] Hayes SC, Luoma JB, Bond FW, et al. Acceptance and com-
1439 mitment therapy: model, processes and outcomes. *Behav*
1440 *Res Ther.* 2006;44:1–25.
- 1441 [89] Hayes SC. Analytic goals and the varieties of scientific con-
1442 textualism. *The act in context.* ?: Routledge; 2015; p.
1443 126–142.
- 1444 [90] Oakman J, Kinsman N, Briggs AM. Working with persistent
1445 pain: an exploration of strategies utilised to stay productive
1446 at work. *J Occup Rehabil.* 2017;27:4–14.
- 1447 [91] Hayes SC. Acceptance and commitment therapy, relational
1448 frame theory, and the third wave of behavioral and cogni-
1449 tive therapies—republished article. *Behav Ther.* 2016;47:
1450 869–885.
- 1451 [92] Conner TS, Barrett LF. Trends in ambulatory self-report: the
1452 role of momentary experience in psychosomatic medicine. *Psychosom*
1453 *Med.* 2012;74:327–337. English.
- 1454 [93] Woolf CJ. Overcoming obstacles to developing new analge-
1455 sics. *Nat Med.* 2010;16:1241–1247.
- 1456
1457
1458
1459
1460
1461
1462
1463
1464
1465
1466
1467
1468
1469
1470
1471
1472
1473
1474
1475
1476
1477
1478
1479
1480
1481
1482
1483
1484
1485
1486
1487
1488
1489
1490
1491
1492
1493
1494
1495
1496
1497
1498
1499
1500
1501
1502
1503
1504
1505
1506
1507
1508
1509
1510
1511
1512