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A healing journey with chronic pain – a meta-ethnography synthesising 195 qualitative studies

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Abstract (250)

Objective: There is a large body of research exploring what it means for a person to live with chronic pain. However, existing research does not help us to understand what it means to recover. We aimed to identify qualitative research that explored the experience of living with chronic pain published since 2012 and to understand the process of recovery.

Design: A synthesis of qualitative research using meta-ethnography.

Methods: We used the seven stages of meta-ethnography. We systematically searched for qualitative research, published since 2012, that explored adults' experience of living with, and being treated for, chronic pain. We used constant comparison to distil the essence of ideas into themes and developed a conceptual model.

Results: We screened 1328 titles and included 195 studies. Our conceptual model indicates that *validation* and *reconnection* can empower a person with chronic pain to embark on a journey of healing. To embark on this journey requires commitment, energy, and support.

Conclusion: The innovation of our study is to conceptualize healing as an ongoing and iterating journey rather than a destination. Health interventions for chronic pain would usefully focus on: validating pain through meaningful and acceptable explanations; validating patients by listening to and valuing their stories; encouraging patients to connect with a meaningful sense of self, to be kind to themselves, and to explore new possibilities for the future; and facilitating safe reconnection with the social world. This could make a real difference to people living with chronic pain who are on their own healing journey.

Chronic pain
Qualitative Research
Qualitative Evidence Synthesis
Patient experience

Introduction

Although the alleviation of pain is integral to healthcare, and despite efforts to understand it, pain often remains a *puzzle* (1). Longstanding pain cannot always be explained biomedically (1), it can persist beyond the expected healing time, and it is not always amenable to treatment (2). It is therefore no surprise that it can have a profound effect on a person's physical, psychological and social wellbeing (3). The biopsychosocial framework rests on the premise that the experience of pain is the result of a complex relationship between biological and psychosocial factors (4). Although this model has gone a long way toward focusing on the human experience of pain, it has been criticised for remaining 'dualistic', particularly in situations where psychosocial approaches are 'grafted' on when no biomedical explanation has been found, or when biomedical interventions have failed (5). In contrast, a more embodied approach focuses on the personal meanings of pain, recognising that pain is a subjective lived experience, regardless of underlying pathology, that is always experienced by *someone*. Each experience of pain is always 'unique to the individual' (6). Understanding the meaning of pain to those who live with it is therefore integral to the study of pain (7). Personal meanings underpin our emotional response and actions. This accords well with the International Association for the Study of Pain (IASP) definition of pain as a sensory *and* emotional experience (8). The recently revised IASP definition includes key notes acknowledging that pain is a personal experience saturated with meanings that are grounded in unique life experiences (8). This experience is embedded in a particular cultural and historical context (9).

One of the aims of qualitative research for healthcare is to listen to people's stories and distil the essence of what it means to experience ill health. This distilled knowledge, in the form of qualitative research *themes*, can be used to help understand people's reaction to illness and treatment, and to improve healthcare. There is a growing body of qualitative research

exploring what it means to live with chronic pain, with at least 20 reviews of this research (10-32) incorporating hundreds of primary studies. In 2017, Toye and colleagues published a synthesis of reviews which included 187 primary research studies published up to 2012 (33) and incorporated the experience of 5236 people living with different forms of chronic pain. This review described the adversarial nature of what it means to live with chronic pain. However, although the review suggested that *recovery* hinges on giving up the search for a biomedical ‘fix’, it did not help us to understand the process or meaning of recovery for those with chronic pain. For example, can a person truly *recover* if pain continues? We aimed to identify qualitative studies published since 2012 in order to build upon existing research and further understand what it means for a person with chronic pain to heal.

Method

We used the methods of meta-ethnography, and the recent guidelines for reporting meta-ethnography (eMERGe)(34). These guidelines report recommendations, guidance, and good practice for conducting the seven phases of a meta-ethnography.

Stage 1: Selecting meta-ethnography and getting started

There are different methods for synthesising the findings of qualitative research: meta-ethnography is a conceptual approach (35). Whereas some reviews amalgamate and describe qualitative research findings, conceptual approaches aim to distil the essence of findings and develop conceptual understanding through a process of abstraction: to make ‘a whole into something more than the parts alone’ (35) (page 28).

Stage 2: Deciding what is relevant

We included primary qualitative research that explored adults’ personal experiences of living with, or having treatment for, chronic pain. Our inclusion criteria were broad as we wanted

to explore the essence of meaning across different contexts, conditions, and populations. We therefore included all primary qualitative studies whose focus of enquiry was chronic pain, as defined by the authors. Table 1 reports the elements of STARLITE (36), which is an acronym that outlines recommended standards for reporting systematic searches of qualitative research: Sampling strategy, Type of study, Approaches, Range of years, Limits, Inclusion and exclusions, Terms used, Electronic sources (36). A single reviewer with more than 20 years of qualitative research experience screened titles and abstracts for relevance (35). Two reviewers appraised full texts and excluded 'irrelevant' or 'fatally flawed' studies (37).

We began our search on Medline, which identifies the vast majority of qualitative studies included in syntheses of qualitative research (20, 38-40). Search strategies for qualitative research differ from quantitative meta-analysis as they do not necessarily aim to be comprehensive. Data collection and analysis are carried out simultaneously, and data collection ends when additional data adds no more insight (theoretical saturation) (41). Campbell and colleagues recommend that 38 studies are adequate for conceptual analysis in a meta-ethnography(42). Due to the sheer number of studies identified on Medline, we did not need to expand our search to additional databases.

Stages 3 & 4: Reading included studies and determining how they are related

Once two reviewers had agreed which studies to include, we uploaded the manuscripts onto Nvivo 11 software(43). Two reviewers read the studies in alphabetical order, by author, to identify concepts and compared and discussed any differences. The aim of this was to gather a portfolio of concepts from the primary studies. We included concepts from different contexts and extracted contextual information (supplementary file 1) to allow the reader to determine how studies are related to each other.

Stage 5: translating studies into each other

We used NVivo 11 software for qualitative analysis to track our analytical decisions (43). Analysis for meta-ethnography involves a process of idea *abstraction*. Through careful reading, constant comparison and collaboration, reviewers abstract, or *distil*, the essence of concepts found in primary qualitative research. To allow us to build on existing research, we used an *index paper* to orientate our analysis as recommended by Campbell and colleagues for meta-ethnography (42). An index paper serves as a point of comparison for analysis by using its findings as *sensitising concepts* (44). As some might argue that using an index paper is comparable to being constrained by a priori concepts, we chose a synthesis of reviews that drew upon 187 qualitative studies and more than 5000 accounts from people living with chronic pain (33). The index findings from this review were: my life is impoverished and confined; I am struggling against my body to be me; I have lost my personal credibility; I am trying to keep up appearances; I need to be treated with dignity; I am on a quest for the diagnostic ‘holy grail’; and deciding to end the quest for the grail is not easy. Using Nvivo software, three reviewers mapped the portfolio of concepts onto the index findings. If any of the three reviewers felt that particular concepts did not map comfortably onto the index finding, or they added insight, or they helped us to understand the meaning of recovery, these concepts were organised into additional conceptual categories through a collaborative process of constant comparison. Index findings and additional categories were further abstracted into overarching themes.

Stages 6 & 7: Synthesising translations and expressing the synthesis

Three reviewers organised the themes into a storyline or ‘conceptual model’. Noblit & Hare describe this as a line of argument or ‘a grounded theory that puts the similarities and differences between studies into interpretive order’ (35) (page 64). This is done through a

process of comparison, thinking and discussion. Multiple draft versions of a model are made before reaching a final agreement on a model that synthesises ideas into a line of argument.

Results

Figure 1 illustrates our search process. We screened 1328 titles and considered 209 full texts exploring the experience of living with chronic pain. We excluded 14 studies for the following reasons: it was not primary qualitative study (45), we were unable to extract a concept (46-50), or the study was outside our scope. For example, the findings did not distinguish chronic pain experience from other conditions (51) or from acute pain (52-55), or reported mixed (56, 57) or irrelevant samples (58). We included 195 reports (59-253) of 170 unique studies, exploring the experience of at least 3589 people (1002 men) with chronic pain. The age of participants ranged from 19-93.

Only ten papers (six unique studies) specifically explored the experience of adults over the age of 60 years (84, 89, 90, 204, 205, 214, 235-237, 242). Studies included participants from a range of geographical areas: USA (n=57), UK (n=31), Sweden (n=19), Norway (n=17), Canada (n=13), Australia (n=8), Denmark (n=7), Spain (n=7), Finland, (n=6), Switzerland (n=5), France (n=3), Ireland (n=3), New Zealand (n=3), South Africa (n=3), The Netherlands (n=2), 3 studies compared two or three countries (Spain & Brazil; Australia and Ireland; Thailand, UK and the Netherlands), and a single study each from Belgium, Brazil, Croatia, Japan, Malaysia, and Singapore. The majority of studies explored the experience of adults in high income countries, in particular the USA and UK. Supplementary file 1 shows the topic and context of each study, the data collection and analytic method, and the number of participants along with their gender and age range.

We organised concepts, through abstraction, into ten themes (figure 2) which we describe and illustrate with an example of a concept from the primary studies. The exemplars shown are

our interpretations of findings from the primary studies, written in the first person, and are not verbatim narrative. Four of these themes describe what it means to live with chronic pain, and six of the themes describe what it means to be on a healing journey with pain.

What does it mean to live with chronic pain?

Four of the ten themes distil the essence of what it can mean to live with chronic pain.

My pain is in-validated

This theme, supported by 54 studies (63, 67, 70, 72, 73, 76, 78, 80-82, 86, 88, 91, 93, 100, 101, 106, 109, 110, 114, 116, 119, 121, 132, 145, 153, 154, 160, 173, 175, 176, 183, 185, 187, 191, 193, 195, 200, 202, 206, 208, 210, 211, 215, 221-224, 231, 233, 242, 248, 250, 251) resonated with the index theme '*Quest for the diagnostic 'holy grail'*' (33). The index theme described the feeling that if medical professionals cannot find a biomedical reason for my pain, then nobody will believe my pain is real. Having real pain means there must be something wrong or else 'why would it hurt?' (33). Similarly, our theme describes chronic pain experienced as something that is considered *unreal* and highlights the need for pain to be recognized and validated by others as a *real* condition. For example:

PEILOT ET AL (206): My pain had become overwhelming and I needed some explanations. I needed to make sense of pain and find some order.

There was a sense that a medical diagnosis was the only way that pain could be validated, understood, and recognized by others. For example:

MATHIAS 2014(164): It is hard when you have nothing to show for it. It is intangible to others. I want to understand pain and to be understood.

I am in-validated

This theme, supported by 97 studies (61-63, 65-67, 70, 72-74, 76, 78-82, 86, 88, 91, 93-95, 99-104, 106, 109, 110, 114, 116, 119-122, 124-126, 130, 132-134, 136, 138, 143, 145, 150, 153, 154, 156, 159, 162, 169-172, 176, 180, 181, 183-188, 190, 191, 193, 195, 197, 200, 202, 206, 208, 210, 211, 216, 221-224, 229-234, 238, 242, 244, 248-251, 253), describes the experience of lost personal validation, and highlights the need to be recognised as a fellow human being worthy of dignity. The theme resonated with two index themes. First, '*Lost personal credibility*' which described the feeling that no one believes or trusts me when I say that I am in pain (33). For example:

NORTVEDT 2016 (189): I am rejected at work by managers and co-workers. They don't understand pain. They trivialize my pain. They judge me. They are indifferent. They condemn. Pain and sadness are invisible. I can't explain my pain. They think I can't do a good job. It is humiliating and shameful at work. I am excluded.

Second, '*I need to be treated with dignity*' which described how no one is hearing my story or treating me with dignity, and how I am being sent around in circles by healthcare professionals (33). For example:

HALLSTAM 2015 (125): I waited so long to see a specialist. I feel judged and mistrusted by the health professional. My hopes are dashed. It is so disappointing. They don't care. They don't understand. I feel insecure because they are skeptical. My expectations for help have dropped.

I have been torn apart from me

This theme, supported by 101 studies (61-64, 66-68, 70, 72-75, 77, 79, 80, 82, 83, 86, 88, 92, 95-101, 104, 108, 114-116, 118-122, 125, 127, 128, 131, 133, 134, 138, 139, 143, 146, 151, 153, 154, 158, 161-163, 173, 176, 179, 181-183, 185-189, 194-199, 201, 202, 206, 208, 210,

211, 215, 217, 218, 220-224, 226-232, 235-237, 240, 242, 244, 246, 251, 253) resonated with two index findings. First, 'I am struggling against my body to be me' which described a struggle to maintain my own identity, a feeling that my body is a malevolent presence, and a sense that that I am 'irreparably altered' by pain (33). Similarly, our findings describe a person torn apart from their own sense of self. For example:

KIRKMAN 2015 (146): There was before and then after pain. The old me was connected. The new me is trapped. I am no longer my old self. I was happy. I was confident. I had energy. I live half a life now. I want my old self back.

Second, '*trying to keep up appearances*', which described how I keep my pain to myself so that other people think that I am still the same (*good*) person, and so that they don't judge me as being weak (33). Similarly, our findings describe the need to keep up appearances. For example:

BIGUET 2016 (73): I feel ashamed that I am not the person that I was: I feel useless. I would rather hide from others than look like I am selfish or unhelpful or anti-social. I have to make others understand that I am not a fake. It is stressful explaining to people. It is an assault on me.

However, we also identified concepts that added insight to the index findings and developed a conceptual category: '*I feel ashamed and guilty*' which describes how I have lost my dignity. I have no self-esteem. I feel inadequate. I am worthless. I am useless. I don't deserve love. I am no longer a person. For example:

SMITH 2018 (230): I am ashamed. People don't understand. They blame me. I feel that I am being punished for seeking pain relief. My sense of identity is damaged by others. It is dehumanizing.

I have been torn apart from my world

This theme, supported by 119 studies (59-64, 66-69, 71, 73, 75-78, 80-83, 85, 86, 88, 89, 91, 92, 95-101, 103, 104, 108, 109, 111, 114-116, 118-122, 125-129, 131, 133, 134, 138, 139, 142, 143, 146, 147, 151, 153-156, 158, 159, 161-163, 176, 179, 181, 186-189, 191, 192, 194-198, 201, 203, 205, 206, 208, 210-212, 214, 215, 217-224, 226, 229-232, 235-237, 240-242, 244-246, 250, 251, 253) resonated with the index finding, '*life impoverished and confined*' which described the all- pervading nature of pain, which means that I am ' confined to live in the moment' and uncertain of the future (33). Similarly, our theme describes a person who has been torn apart from their world and left disenfranchised and isolated. For example:

SNELGROVE 2013(231) : I observe life and do not participate. I am stuck in time and set apart from mainstream living. Nothing changes. I observe life and do not participate. I have good and bad days. It is a paradox, stuck in one place in time, yet unpredictable and variable.

We also identified concepts that added insight to the index finding and developed three additional conceptual categories: First, '*I had hit rock bottom*': I was in the dark with no foothold. I was in chaos. I was exhausted. I was hopeless. I had reached an impasse (a position from which there seemed to be no way of escape). Things are so bad that there was nowhere else to go. For example:

SMITH 2018 (230) : Nothing but medication works. Health professionals don't take the time to listen or to help. They can be caring or cruel. It is a paradox. The non-drug therapies are limited and constricted. I am at an impasse: a closing of possibilities for pain relief.

Second, '*I am disenfranchised*': I do not feel like I am part of this society and culture. I feel like an alien. Things are not fair. I suffer discrimination. There are cultural barriers. I am

living in a body that no one here understands. I am overlooked and disregarded. I am a second-class citizen. I am isolated. I am an outsider. For example:

Nortvedt 2016(189): I am shut in my house. My husband rarely wants to go out. I am ashamed because he maltreats me. I feel like a captive. I just sit home alone and think. I have lost my network, my extended family, and friends. I feel secluded and ashamed. I don't speak the language. I can't talk to health professionals. I no longer have a network of people to support me. I am exhausted and don't feel like being with others. I feel low. I feel homesick.

Third, *'I have lived through trauma'*: My life was tough even before I had pain. I had traumatic relationships. I carry a lot of trauma. I lived in poor conditions. I was not in control of my own life. I had losses. I have been broken by life events. For example:

ALLEN 2015(62): Life was tough and it is still tough: Unstable relationships, lack of family support, past and current trauma You carry trauma.

What does it mean to be on a healing journey?

Six of the ten final themes developed understanding about what it means to be on a journey of healing.

My pain has been validated

This theme, supported by 20 studies (64, 73, 88, 114, 116, 117, 125, 128, 144, 152, 157, 164, 191, 193, 206, 208, 216, 218, 220, 248), describes the experience of having a meaningful and acceptable explanation for chronic pain. Being on a healing journey means that 'I have made sense of my pain': My pain is real. I now understand my pain better. My pain no longer frightens me. It is no longer threatening. I am less afraid and anxious. I feel that I can

manage. I have some control back. I understand my body and pain and am starting a new journey. I have gone from chaos to comprehensibility and manageability. For example:

HALLSTAM 2015 (125): The penny's dropped. I started to realize that there was a link between my pain and my own thoughts and actions. I could then start to manage things differently. In pain management they gave me a proper explanation of why I have this pain. They acknowledged the reality of my pain and made me feel accepted as an individual.

There was a sense that understanding pain gave a sense of control and made it less threatening.

PIETILÄ HOLMNER 2018(208): I learned about chronic pain and its effects. I felt less afraid and anxious. I felt that I could manage. I understood that pain is not in my mind. I have learnt about the complexity of pain and what contributes to it. I realized that I was thinking negatively and that this had to change.

I have been validated

This theme, supported by 20 studies (66, 67, 69, 70, 76, 89, 98, 107, 117, 118, 125, 164, 190, 192, 206, 208, 213, 241, 248, 252), describes a sense of validation as a human being through finding a voice and being heard by others. A healing journey means *giving voice to my pain: being heard and validated*: I have found my voice. My suffering is given voice and is understood. I had time to tell my story. I wasn't held back by fear of being judged. People listen to me, hear me, and see me. I am validated, believed, and taken seriously. Being validated was life changing. It empowers me. For example:

ARMAN 2016 (66): My suffering is given voice. My suffering has been understood. My story of suffering is confirmed.

There was a sense that being given a platform to be heard opened the possibility of renewed understanding and change: a way forward.

PEILOT 2014 (206) : At pain management I opened up my feelings to others and was able to change. It opened up the possibility of new meaning. I could take off my mask and now I can communicate my pain. I was allowed to talk.

I am reconnected with myself

This theme, supported by 58 studies (62, 64-66, 69-71, 73, 92, 94, 96, 107, 108, 111, 112, 117, 118, 121, 122, 125, 133, 135, 137, 141, 148, 152, 154, 155, 157, 160, 164, 171, 173, 176, 186, 188, 190, 193, 195, 196, 206-208, 211, 213, 218, 221, 223, 224, 226, 228, 231, 238, 243, 247-249, 253), describes a sense that I have been reconnected with my sense of self and I am exploring a new identity where I can live peacefully alongside pain. It is underpinned by four conceptual categories that help to understand what it means to heal through self-connection. First, *I have integrated my body, mind, and self: I am whole*: I have a new relationship with myself and my pain. Pain is not my identity. I am still me. Pain is part of my life experience. I am living alongside pain. It no longer dominates me. Pain is just there. It is lighter. I understand my body now, and how my body and mind are connected. I have reengaged with who I am: my core self. I have restored my sense of self. I am at peace.

BIGUET 2016 (73): My pain has become familiar to me and no longer frightens me. It no longer controls me. Pain is not a separate entity. Accepting is about reintegrating me with my body. I listen to my body and my body and mind work together. My body sets limits but is also how I fulfil my needs. My body is a source of possibilities (and

yet also a hindrance). My body is able, but in a different way. The pain is more in the background. I am still me. Don't compare yourself to others or your old self.

Second, *I am kinder to myself*: I am learning to be more compassionate with myself and to look after myself. I am worthy of this self-compassion. I am allowed to be kind to myself. I am no longer ashamed. I recognize my limits. I no longer feel guilty if I can't do something. I don't have to be perfect. I no longer beat myself up. I am gentle with myself. I learnt to focus on what is important, on what I value. I take care of myself. I ask for help. I take my time and adjust. I do things at my own pace.

PUGH 2014 (211): Working within my limits has made me self-aware. I now ignore mantras from the past, like "Work as hard as you can and do your best." I don't need to soldier on. Our culture is ceaseless striving. It's a gentle challenge.

Third, *I can be still*: I am calmer. I have a sense of stillness and relaxation. I am focusing on a simpler life, close to nature and other humans. I have found a place where I can be still and calm: a place for reflection and learning. I have moved away from chaos. I can be present in the moment. I have found an inner happiness. I am at peace with myself.

OJALA 2015B(195): I am calmer: more confident. Life is clearer and simpler, with mercy and permission to be optimistic about future.

Finally, *I have grown*: I have changed. I have grown as a person. I have been helped by others and can help others. I want to be strong and to give back to the community. I have learnt that I can be valuable and am valued in spite of pain. My experience has made me grow as a person and I want to reciprocate and make a positive contribution to the group and society.

FINLAY 2018(112): I now play an active part in organizing the support group. I put my money where my mouth is. I am proud of what I do. I have grown in confidence. We have different levels of energy and contribute what we can.

I am reconnected with the world

This theme, supported by 60 studies (61, 62, 66, 67, 69, 71, 90, 92, 94, 103, 107, 111-114, 116, 118, 119, 124, 125, 127, 128, 137, 138, 140, 149, 152, 154, 155, 164, 165, 167, 169, 170, 172, 176-178, 185, 188, 190, 192, 193, 195, 202, 203, 206, 208, 209, 211, 213, 218, 223, 233, 234, 238, 247-249, 253) describes reconnection with the world and a sense that I have found a safe place to be. It is underpinned by three conceptual categories. First, *a fellowship where I am no longer alone*: I have found a community who share my experience. I no longer feel alone. There is a sense of togetherness. We understand, care for, and respect each other. We listen to each other without judgement. We encourage and support one another. We have a fellowship where pain goes without saying and we are not defined by pain. The collective is restorative. It helps me cope. It energises. I feel connected to others. I can be myself. I belong.

FINLAY 2016 (111): At pain management I finally met people who understood my experience. I met people who share my experience in the support group. I am free not to be judged by others. I am integrated not isolated. I am bolstered. When you are a group you see that things are worse for others. I have re-evaluated my condition.

Second, *I have found humanity in healthcare*: The health professional treats me as a fellow human being. I am a person not a body part. I am treated with dignity. They listen, they are interested in me, and they care about me. I am taken seriously. I am believed, validated, and

seen. I am treated with kindness and compassion. Being validated was life changing. I have longed for this humanity.

ARMAN 2016 (66) The health professional makes me feel like I am a worthy, whole and suffering human being. My story of suffering is confirmed. I have longed for this humanity. I am touched by the compassion I have received. The health professionals demonstrate an ideal that I have forgotten.

Third, *I feel safe*: an atmosphere was created where I felt understood, safe and looked after. I am living in a different way not driven by fear. I feel less afraid and anxious. I am safe and supported. I feel comfortable, at ease, connected, and understood. The group was a ‘safety parachute’ (111).

PUGH 2014: They encourage me to do things that I was afraid of. I felt safe.

I am empowered

This theme, supported by 57 studies (62, 64, 66, 73, 79, 88, 92, 95, 99, 107, 111-114, 116, 118, 125, 127, 128, 135, 137, 138, 143, 148, 149, 151, 152, 154, 155, 158, 160, 164, 169, 171, 172, 176, 183, 188, 193, 195, 202, 203, 206, 211, 213, 215, 217, 218, 223, 226, 228, 233, 234, 243, 247-249), describes a growth in personal power that allows me to move forward. It is underpinned by three conceptual categories. First, *I am an equal partner*: my health professional treats me like an equal partner. I am respected. We work as a team and make decisions together. We developed a partnership. It empowered me. It restored me as a person. It restored my self-esteem. This makes me feel more secure and confident. We share responsibility.

WILSON 2017 (249): It was not them and us. It felt like we shared the responsibility for treatment.

Second, *I have power & autonomy*: I became aware of my own strength. I have become more resilient. I have strength, autonomy, and power. I have found a new confident self with greater self-esteem. I am proud, resilient, and confident. I believe in me. I have discovered power within myself. I can take some action. I felt that I could now do things for myself. I want to take care of myself. I feel empowered. I can do the things that I want to. I am living life.

ARMAN 2016 (66): Signs of self-care: I am finding new ways to think, be and live. I am inspired to change. I am learning to trust in my own ability to take care for myself. I have come home.

Finally, *I am building strategies*: I have learnt new ways of doing and being. I am finding ways to keep the tank full. I have experimented with lots of things: not all have worked but I am finding out what does work. I have learnt strategies to self-manage pain. I am building a repertoire of skills that help me to manage pain: a toolbox. It is useful to have tangible things to do in order to make a start. I can take some action. I am proactive, rather than reactive. I have meaningful goals and a plan to achieve them. It has empowered me. I have learnt techniques for dealing with my pain. I have become active in my own healing.

HALLSTAM 2015(125): I have new coping strategies (regular exercise, dealing with emotions, setting goals, pacing). I am a new me. I am proud of myself

I have a future

This theme, supported by 61 studies (59, 60, 64-66, 71, 73, 79, 84, 87, 88, 101-103, 107, 111, 112, 114-118, 121, 125, 127, 129, 135, 137, 139, 140, 148, 152, 154, 155, 157, 164, 169, 171, 172, 178, 186, 190, 192, 193, 195, 196, 201, 206-208, 211, 213, 216, 218, 223, 228, 235, 243, 247-249), describes living a world in which I can envisage a future: this requires dedication and commitment. It is underpinned by four conceptual categories. First, *I am seeing the world*

through a new lens: I have changed my perspective. I have a new outlook on life. I have learnt to think differently about my pain. I am finding new ways to think, be and live. I have found meaning. I am determined to live well with pain. I owe it to myself. I live life. I find joy. Life is clearer and simpler, with mercy and permission to be optimistic about future. I've learnt to focus on what is important. I value the little things and those I love. I focus on what I can do, rather than what I can't do. I can live well with pain.

FINLAY 2018(112): I have changed my perspective. I can pursue my own interests: I can get out and be sociable. Being in the group has shown me that I can get out into society again. I have learnt that I can be valuable and am valued despite pain.

Second, *I am open to possibilities*: I have made a new start and I am open to possibilities. I have hope and can see a way forward. I have learnt new ways of doing and being. I can experiment and be creative. I want to learn. I am optimistic. I am curious. I feel safe. I can do more and am ready to explore new things. I can pursue my interests and be sociable. I want to find meaningful things to do. I can have pain and still live a full life.

WILSON 2017 (249): It made me free to experiment. I wasn't held back by fear of being judged. I became more aware of things that influenced my pain: body sensations, thoughts, and emotions. It encouraged me to try different things. I became self-aware. I became more willing to experiment.

Third, *acceptance is not giving up*: I have learnt to accept. I accept that I have limitations. I accept that I am different to what I was before. Yet I am still me. It is not giving up; it is moving forward. It has allowed me to move on. I have accepted that pain is part of my life, but I can still live. I have gained freedom through acceptance. Acceptance has made me see that I can have a better life. This has empowered me.

OJALA 2015B (195): My life is better since I have accepted my pain. I have grown as a person. I am calmer: more confident. Life was clearer and simpler, with mercy and permission to be optimistic about future. Acceptance has made me see that I can have a better life. I see that pain is just pain and that it does not need to affect your sense of identity. I have found hope in a healthy life.

Finally, *an ongoing journey*: Acceptance is a process. Some days I can accept and other days I cannot. It is complex. It can be a struggle. It needs practice and perseverance. It takes time. It is hard to change. It can open painful experience. It can be emotional. You have to peel back the layers. It takes courage. Being validated, learning, being with others helps you to learn to accept.

BIGUET 2016(73): acceptance as an equivocal project: I know that I have to accept, to move on, but acceptance is complex; it is a struggle; it is ambivalent. To accept you need to understand that the pain is here to stay. I have to accept that my body is both a resource and a hindrance Acceptance is a personal challenge which I must give time and prioritize.

Conceptual model – a healing journey

Our conceptual model, integrating the ten final themes, is shown in figure 3. The model helps us to understand what it means to be on a healing journey with pain. First, healing means that I am no longer experiencing my pain and myself as invalid. Validation of pain means to have received a meaningful and acceptable explanation for pain: Validation of myself means being recognised as worthwhile and finding a voice that is heard. Second, healing means that I am reconnecting with myself and my world. Reconnection with myself means that I am forging an emerging self who can live in peace alongside pain, and who is allowed to be self-compassionate. Reconnection with the world means that I am finding a safe place in the

world, where I am no longer alone and where I am treated with humanity by others.

Validation and reconnection are processes that empower me to embark upon a healing journey towards the future. We conceptualise this as an ongoing and iterating journey of healing rather than as a final destination of recovery.

Discussion

Our findings build on published research to further understand the meaning of recovery from chronic pain through the methods of meta-ethnography. Conceptual analyses of qualitative data, such as grounded theory or meta-ethnography are interpretations of qualitative data. This interpretive act is the strength, rather than weakness, of qualitative approaches. Analyses rely on a rigorous approach to the data combined with intuitive and creative processes. Qualitative research epistemologies acknowledge perspective and seek to challenge this through a dialectic process of enquiry and critical collaboration.

We synthesized findings from 195 primary qualitative research studies incorporating more than 3000 people with chronic pain into a conceptual model. Findings indicate that to embark on a healing journey requires validation (of pain and self) and reconnection (with self and the world). Being invalidated and disconnected *disempower*; it means feeling obsolete and having neither force nor strength to move forward. In contrast, being valid and connected *empower*; it means feeling valued, significant, or worthwhile. This is central to a person's sense of dignity – 'the quality of being worthy or honourable' (Oxford English Dictionary), which is integral to well-being and thus to effective healthcare. Feeling invalid and disconnected resonates with Frank's *Chaos Narrative* (254). Frank distinguished three narratives that people use to make sense of illness: first, the culturally preferred *Restitution Narrative* which tells the story that my body becomes sick, I find out what is wrong, and then I am restored. Frank recognises that this does not fit the experience of chronic illness.

Second, the *Chaos Narrative*, which is paradoxically an *anti-narrative* with no decipherable storyline. Chaos is a space of contingency, loss of control, an impasse, a place where I am ‘hammered out of self-recognition’ (254) and isolated from others, a place where I have no voice. Finally, *the Quest Narrative* describes a space where a person accepts contingency and meets suffering head on, a space where ‘losses continue to be mourned but the emphasis is on gains’(254). This resonates with our journey of healing. There is a sense that in order to move forward to a brighter future, a person with chronic pain must reconceptualise their experience. In this way, Turner describes chaos as *fructile*: ‘a storehouse of possibilities . . . a striving after new forms . . . a gestation process’ (255). Our conceptual model suggests that validation (of pain *and* self), and reconnection (with self and others) empowers a person to begin a healing journey. Our model also indicates that this is an ongoing, iterating journey, where (perhaps) ‘renewal is never complete’(254). It requires ongoing commitment, energy and support and there may be reasons why some people are not able to move forward. As such, Frank warns us to avoid the risk of depreciating those who ‘fail to rise out of their own ashes’(254). Our conceptual model may help us to understand some of the barriers to healing.

Our findings are drawn from primary qualitative research that explores the meaning of chronic pain in a wide range of different contexts. We recognise that each person’s experience of living with pain is unique. Our findings suggest that there are some essential themes that distil the meaning of what it is to live with chronic pain, and what it is to embark on a journey of healing. This knowledge can help us to facilitate this journey. Future studies to explore conceptual categories that were supported by fewer studies would also make a meaningful contribution to our understanding what it means to live with chronic pain. For example, studies to explore the experience of those who have been through traumatic experiences that transcend their pain (62, 83, 85, 86, 108, 181, 191, 210, 223, 232), the

experiences of those who feel socially disenfranchised (78, 82, 126, 187-189, 191, 205, 210, 219, 224, 244, 251) and the pain experience of adults older than 60 years (84, 89, 90, 204, 205, 214, 235-237, 242) . We did not identify studies that explored the experience of chronic pain in low- and middle-income countries.

Conclusions

Our findings go beyond previous syntheses that help us to understand what it means to live with chronic pain and highlight possibilities for healing. Although our findings resonate with existing qualitative research, our innovation is to reconceptualize recovery as a *journey of healing* rather than a destination. Six of our ten final themes help us to understand what it means to embark on this journey: my pain has been validated, I have been validated, I am reconnected with myself, I am reconnected with the world, I am empowered, and I have a future. Health interventions for chronic pain would usefully focus on: (a) validating pain through meaningful and rational explanations; (b) validating patients by listening to and valuing their stories; (c) encouraging patients to connect with a meaningful sense of self, to be kind to themselves, and to explore new possibilities for the future; and (d) facilitating safe reconnection with the social world. Our findings suggest that this focus could empower people living with chronic towards a meaningful future.

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Tables

Table 1: Elements of STARLITE for reporting qualitative literature searches (sampling strategy, type of study, approaches, range of years, limits, inclusion and exclusions, terms used, electronic sources)

Figure legends

Figure 1: shows the number of records identified, screened, excluded, and included.

Figure 2: shows the organisation of conceptual categories into themes.

Figure 3: shows our conceptual model - a healing journey with chronic pain, described in the results section.