

*This is an Accepted Manuscript of an article published by Taylor & Francis:  
Raffaella Kurz & Clair Hebron (2022) "Finding a new normal: the lived  
experience of persons' journey towards coping with persistent low back  
pain", Physiotherapy Theory and Practice,  
DOI: [10.1080/09593985.2022.2144782](https://doi.org/10.1080/09593985.2022.2144782)*

## **"Finding a new normal: the lived experience of persons' journey towards coping with persistent low back pain"**

Introduction: Persistent low back pain (PLBP) is the biggest global cause of disability. Persons with PLBP experience biographic disruption and existential crisis. Guidelines recommend a biopsychosocial approach to management, with the emphasis on coping strategies.

Purpose: However, there is a paucity of research exploring the lived experience of persons who self-identify as coping with PLBP.

Method: The study used an interpretive phenomenological approach, analysing transcripts from 1:1 interviews with six persons who self-identify as coping with PLBP. Poetic language was used to elicit empathic, embodied relational understanding and convey a richer understanding of the phenomenon that authentic quotations might not be able to reveal.

Findings and Conclusion: Participants' descriptions conveyed the sense of a journey, starting with the loss of a sense of self as they engaged in the pain battle, followed by a transition towards a new 'normal', in which time, acceptance and trust in their own intuition were meaningful components. Although anxiety and fear were a continued presence, but they became more manageable. Society's role in the coping process was significantly meaningful and is something which requires reflections from therapists' and more widely.

**Keywords: coping; low back pain; poetry; phenomenology**

## INTRODUCTION

Globally, low back pain (LBP) is the leading cause of years lived with disabilities (Wu et al, 2020). It has been estimated that 84% of the population will develop LBP at some point in their lives and around 20% will become persistent sufferers (Balagué, Mannion, Pellisé, Cedraschi 2012; Meucci, Fassa, Faria, 2015). The majority of LBP is termed “non-specific low back pain” as no distinct or reliable pathology can be identified (Balagué, Mannion, Pellisé, Cedraschi, 2012; Deyo and Weinstein, 2001). This lack of a clear medical diagnosis can create uncertainty, with those experiencing pain finding it difficult to understand why their symptoms are ongoing (Toye et al, 2013). Persons with PLBP are likely to continue to search for a medical cause not only in the hope of finding effective treatment or a cure (van Griensven, 2015), but also to legitimise their pain to others (MacNeela et al, 2015; Toye et al, 2013; van Griensven, 2015). In addition to the pain, uncertainty and disbelief were reported to have a negative impact on the individuals’ wellbeing (Bailly et al, 2015; Bunzli et al, 2013; MacNeela et al, 2015). Persons with PLBP have described withdrawal from family and social events (MacNeela et al, 2015; Smith and Osborn, 2007; Snelgrove, Edwards, Lioffi, 2013), changes in personality and a loss of empathy for others (Smith and Osborn, 2007; van Griensven, 2015). Findings from qualitative research reveal a sense of existential crisis, whereby persons with PLBP felt they were unable to be themselves anymore. Their testimonies convey the loss of a sense of self, low mood, anxiety and depression (Snelgrove, Edwards, Lioffi, 2013). PLBP can last for many years and, for some, a lifetime and thus developing better understanding of the experience of PLBP and how persons learn to live with and manage their symptoms is crucial

in optimizing care.

Contemporary management of persons suffering from PLBP uses a biopsychosocial approach. This is reflected in most international guidelines (Meroni et al, 2021) which emphasise self-management strategies, including a combination of physical and psychological treatment programmes tailored to the individual needs of the person in care. Although therapists recognise the need to include self-management strategies into their treatment plans, there are challenges to them operationalizing this in practice (Hutting, Oswald, Staal, Heerkens, 2020).

The aim of the self - management approach is to help the person to live with the condition if pain persists and there is evidence that some persons with PLBP learn to successfully self-manage their pain and are able to live well with the condition (Bunzli et al, 2013; MacNeela et al, 2015; Toye and Barker, 2012). In the literature, qualitative studies have explored the experience of persons living well with chronic pain (Lennox Thompson, Gage, Kirk, 2020; Owens et al, 2016) or chronic nonspecific musculoskeletal pain (de Vries et al, 2011). To the authors' knowledge, however, no previous study has explored the lived experience of persons self-identifying as coping with PLBP. Gaining a better understanding from those who have found a way of living with PLBP, pursues Antonovsky's salutogenesis theory, promoting the origin of health, rather the traditional pathogenic focus in health care, aiming to challenge the origin of disease and its associated risk factors (Mittelmark and Bauer, 2022). In addition, gaining a better understanding may enable therapists to cultivate more authentic and empathetic feelings and so may become better partners with

persons receiving their care. Clinicians' empathy is valued by care seekers (Dima et al, 2013; Singh et al, 2018) and provokes a feeling of being understood, creating a safe space in which to speak freely about learning how to flourish whilst living with symptoms. Therefore this study aimed to explore the lived experience of learning to cope with PLBP.

## METHODS

### Study design

This study used an interpretive (hermeneutic) phenomenological framework drawing on Heidegger's interpretive phenomenological approach and Dahlberg, Dahlberg, and Nyström (2008) reflective lifeworld research. For Heidegger, human beings are always 'thrown' into the world, in a given context and culture, from which their realities cannot be separated (Converse, 2012; Finlay, 2009; Neubauer, Witkop, Varpio, 2019). Therefore, interpretive phenomenology goes beyond participants' descriptions, by interpreting their accounts through their lifeworld (Dahlberg, Dahlberg, Nyström, 2008, p. 73; Matua and Van Der Wal, 2015; Neubauer, Witkop, Varpio, 2019). As a result, the researcher is looking for hidden meaning by interpreting the experience using their own thoughts and experiences (Ashworth, 2016). This study also draws on van Manen's by using his work on evocative phenomenological writing and poetic expression (van Manen, 2014, pp. 261-267).

### Recruitment

In a phenomenological enquiry a small number of participants are recruited, as accounts need to have enough richness and experiential examples to allow a

deep understanding of the lived experience of each individual and enable cross-case theme analysis (Creswell and Poth, 2017, p. 161; Dahlberg, Dahlberg, Nyström, 2008, pp. 175-176; van Manen, 2014, pp. 352-353). Too many may lead to superficial analysis, hence, six participants were purposively recruited by responding to an advertisement on social media seeking participants who had experienced LBP for at least two years and identified themselves as coping with their symptoms. This number of participants is in line with other phenomenological enquiries (Blank, Finlay, Prior, 2016; Fitzpatrick and Finlay, 2008; Osborn and Smith, 2006).

All participants were based in the UK, over 18 years of age and had received multiple conservative interventions in the past. In addition, two had received injections and one person had undergone surgery. Further participant information is provided in Table 2.

#### [TABLE 2]

Participants were offered a choice of either a face-to-face interview in a private room in a university library or virtually using Skype or telephone. Interviews took place between November 2019 and January 2020, prior to the global pandemic.

#### Ethics

Potential participants who contacted the first author in response to a social media advertisement were sent an information sheet and provided written consent prior to the interviews. Ethical approval was gained from a university ethics and governance committee in the south east of England.

## Data collection

Data was collected via semi-structured individual interviews. Prior to the interviews the first author, a musculoskeletal physiotherapist who has worked abroad and in the UK for several years and has personal experience of PLBP, sought to adopt a phenomenological attitude. This required her to look beyond the already-known, taken-for-granted “natural attitude”. She aimed to bridle her preconceptions, assumptions and foreknowledge of the phenomenon in order to allow the phenomenon to show itself (Dahlberg, Dahlberg, Nyström, 2008, pp. 129-134) and become more aware of her preconceptions without completely suspending them, as it is practiced in descriptive phenomenology (Finlay, 2009; Neubauer, Witkop, Varpio, 2019). As the first author had personal experience of the phenomenon of interest, she wrote a fore-conception statement exploring her own past experience, thoughts and understanding of PLBP (Dahlberg, Dahlberg, Nyström, 2008, pp. 134-137; Kvale and Brinkmann, 2009, pp. 30-31). To maintain awareness of her influences on the data, the first author kept a reflexive journal throughout the research process, in which she questioned her interpretations and biases. Being aware of personal bias is important to enable openness and the true reduction of the phenomenon of interest (van Manen, 2014, p. 220), and can be a valuable guide to explore hidden meaning (Finlay, 2009).

The interviews were led by the first author. Two interviews were conducted face-to-face, three were completed via Skype and one over the telephone. All interviews started with a short introduction, as advised by Kvale and Brinkmann (2009, p. 128), followed by questions to gain contextual information. Next, participants were asked to describe, in as much detail as they

possibly could, their life since the back pain started. A follow-up question was: “Can you give me a specific example when you learned a way to cope?”. Additionally, the first author used exploratory prompts to encourage the participant to elaborate on an interesting experience or expression related to the phenomenon of interest (Kvale and Brinkmann, 2009, p. 135). Notes were taken at the time about statements that the researcher wished to explore in depth at a later stage of the interview as well as gestures and non-verbal cues. Afterwards, a short reflection on the researcher’s first impressions was captured. The duration of the interviews varied from 33min to 93min, concluding when it was felt that the participant had exhausted their experience. Each interview ended with an opportunity for the interviewee to add further information if they felt an important part of their experience had not been discussed.

### Data analysis

The interviews were audio-recorded, transcribed verbatim and anonymised by the first author and pseudonyms were assigned. Next phenomenological analysis was applied to each individual’s account and later used to cross-examine the collective whole (Stenner, Mitchell, Palmer, 2016). A thorough reading and re-reading of the transcripts aided a deeper understanding of the data to be obtained and helped the author gain a sense of the whole. Afterwards, meaning units (parts of the text containing a meaning) were identified, ranging from a few words or short sentences to whole paragraphs. Using the researcher’s field notes and reflexive journal, an annotated linguistic, descriptive and conceptual reflection of each meaning unit was compiled, and the researcher took time to dwell in the data and elucidate the hidden meaning.

Following the reflections, a search for thematic meaning for each meaning unit was developed within each participant's account as shown in Table 1 in the supplemental material. The reflexive journal was used to help the researcher to reflect on whether the themes were actually present in the transcripts rather than having emerged purely from her own experience.

After all the interviews were analysed, the first researcher went back to the first interviews and re-evaluated the coherence between the themes of each meaning unit, comments, and the transcript within each account. This practice of "dwelling" (spending time with and re-examining the data), allowed new understandings and implicit meanings to emerge and helped the researcher to distance herself from the data to allow the phenomenon to show itself (Finlay, 2014).

The themes of the first account were printed out and grouped together. After this, themes from other accounts were cross-referenced with the already-existing themes, and included when relevant or new themes were grouped (see Picture 1 in the supplemental material). These themes were later clustered into sub-themes that either stood in contrast to or echoed other thematic units (Picture 2 supplemental material).

Next a creative approach to analysis was used to reach a deeper understanding of the phenomenon. Inspired by van Manen's "Phenomenology of Practice" (2014, pp. 249-267) anecdotes and poetic stanzas were crafted from participants' personal words. The latter was later used as poetic language can help to create a visually and rich sensory image in the reader's mind and thus to sensitize readers to the complexities of coping with PLBP, evoking



empathetic, embodied relational understanding (Todres, 2008) that plain language in the form of quotations might not be able to reveal (van Manen, 2014, p. 261).

This processes involved to shorten sentences by taking out transition words or words or parts of sentences or meaning unit that did not capture the meaning of the theme. Very rarely participants' words were exchanged for synonyms or the order of words were adjusted to allow the stanzas to better flow. The aim, however, was to stay faithful to the meaning, mood and effects of the original transcripts (see for reference supplemental material Table 2).

Visualising sub-themes in form of maps and drawings facilitated imaginative variation and influenced the creation of the master-themes shown in Drawing 1. Heidegger encouraged the use of imaginative variation during analysis in order to clarify the phenomenon's structure and gaining stability of its presentation by imaginatively varying its components (Bevan, 2014). In this study, both authors visualized the sub-themes in maps and drawings, experimenting with ideas of visualizing the content of the sub-themes to gain a sense of the whole. Simultaneously, both authors discussed and explained the structural appearance of the current visual idea. This visualization was then altered or discarded during the conversations until the final visualization of the phenomenon emerged. During this process, the authors also used the hermeneutic circle by moving backwards and forwards between the single part (themes and sub-themes) and the whole data set, with the intention of capturing the nature of the phenomenon (Kvale and Brinkmann, 2009, p. 210).

The second author, an experienced qualitative and phenomenological

researcher, musculoskeletal physiotherapist and academic, familiarised herself with the transcripts. She then entered into dialogic discussions with the first author, offering alternative interpretations, and engaging in all stages of the outlined phenomenological analysis in great detail. The poetic stanzas were again discussed intensively and crafted by both authors. The analysis finally ended with the finished written enquiry as through writing, reading and adjusting the written words, more meaningful insight was gained (van Manen, 2014, p. 367).

### Trustworthiness

The audit trail and the supplementary material illustrates the transparency of the analysis. Additionally, the intense and open discussions between the first and second author, by challenging each other's interpretations and pre-understanding, enhance the credibility of the findings. Finally, the first author sought to maintain a critical reflective perspective throughout the data collection, analysis and writing process, while spending several months dwelling on the data, in an attempt to capture the lived experience of coping with PLBP. In line with the concept of information power in qualitative researcher, the authors ensured that participants provided rich and varied examples of concrete situations revealing new knowledge of the meaning of learning to cope with PLBP (Malterud, Siersma, Guassora, 2016). As interpretive phenomenology aims to evoke the unique and hidden meanings of an experience rather than its repetitive patterns, data saturation was not intended for this study (van Manen, 2014, p. 347). Likewise "member checking" has not been completed, as interpretive phenomenology does not reflect or represent a participants'

experience only as they understand it (Finlay, 2009). The researcher adopts the phenomenological attitude and uses their fore-understanding in a reflexive manner to identify hidden meaning of which the interviewee was not aware: participants cannot prove or disprove the analysis (Braun and Clarke, 2013, p. 285).

### FINDINGS

Three master-themes represented the different stages on a journey towards coping. This started with the loss of a sense of self, followed by the pain battle and travelling towards a new normal. The master-themes and their sub-themes are shown in Drawing 1.

[Drawing 1]

The drawing starts with a rope, consisting of four cords tightly intertwined with each other. These four cords represent the sub-themes of mood, relationships, society and personal background, which together form the sense of self. Participants' descriptions revealed that when pain (symbolised by the black fibres) remains over time, it infiltrates the sense of self as a whole and the tight interconnection between the cords starts to loosen and break apart. This leads to the loss of a sense of self, the first master-theme. Losing the sense of self was conveyed as being meaningfully interrelated with mood, previous established personal relationships, the person's own understanding of themselves as an individual and their interaction with the wider society and professional communities.

Participants' accounts conveyed the sense of chaos that characterised the second master-theme, the pain battle, where personal beliefs about the cause of pain, the trial-and-error process of new management strategies and

the loss of previous successful strategies are in constant exchange.

Participants' narrative revealed that over time (often years), as an acceptance of pain developed alongside a trust in personal intuition, a new structure slowly emerged, forming the last master-theme, a new normal.

The structure of the new normal is different in shape and appearance. In some places, life appears darker as pain continues to be experienced: but it is now seen more as a continued presence than an infiltrator. Because of continued uncertainty caused by unpredictable and variable pain, the rope appears more fragile and less stable than before, with single fibres appearing to separate now and again symbolising the peaks of variable pain. This also illustrates the fear of once again losing the sense of self. However, some participants revealed positive experiences which are represented in the appearance of some brighter cords. The three themes, representing stages on the journey towards coping, were conveyed as merging, whereby there was uncertainty where one stage ended and the next began.

Next, each master-theme is explored in more detail. To illuminate the meaning of the experience, poetic stanzas were created from participants' descriptions. The poetic stanza can be found in their entirety in the supplemental material Table 3.

#### The loss of a sense of self

All participants conveyed the vast impact of pain on their life, affecting all four cords leading to a loss of their sense of self. A change in mood, characterised by expressions of anxiety and fear, was present in all participants' accounts. Most

participants also described the experience of social withdrawal, with their pain affecting their relationships with *other* persons.

<i>Back pain is tiring, it's there <b>all</b> the time, difficult to ignore. When it keeps me awake at night I'm tired during the day, that brings my mood down, quite frightening, quite low.</i>	<i>I became isolated, withdrawn. Pain just destroyed my life took over my life. The anxiety was running parallel with the pain. Life was pretty shit for a long time.</i>
--	---

(Frank)

(Caroline)

The experienced significance of society's influence was illuminated in participants' descriptions which conveyed the sense of participants being *othered* due to their persistent pain. Participants' perceptions of society's beliefs were meaningfully related to their mood and self-esteem.

*I know people  
who are embarrassed when I am using a stick.  
One actually said:  
"you are too young to be using a stick!"*

(Abigail)

Evelyn expressed her perception that others think they understand because of their own back pain experience. However, in her experience they are unable to truly understand "*how complex it really is*" or her struggle because their back pain has resolved. This appeared meaningful in relation to her mood.

*People who tell me a lot about their pain  
tend to have a little twinge,  
for one day in bed and it's gone forever!*

*But it's a completely different thing  
if it doesn't affect your whole life!  
That's the mental side of it,  
getting my head around people's reactions.*

*People think if something is wrong,  
you have treatment, physio,  
great, you are better!  
But it's actually quite complicated,  
I can't expect everybody to understand.*  
(Evelyn)

Danielle, a physiotherapist, conveyed a sense of disapproval and a perceived lack of acknowledgment from her colleagues. This also seemed meaningful to other participants who described a lack of acknowledgment from healthcare professionals and, like Abigail, from persons within their own communities, which appeared to lead to social withdrawal. Conversely, receiving acknowledgement had a positive impact as illuminated by Danielle.

*At work  
it wasn't appreciated,  
there was a sense of disapproval.  
I think,  
people thought I should be better,  
I think,  
people thought I was attention seeking,  
I think,  
no colleague was ready for the time it took  
apart from the one,  
who was understanding,  
validated my experience,  
that's why I was so grateful.*

(Danielle)

*I withdrew socially because  
people didn't acknowledge me,  
but others have also withdrawn from me  
as I wasn't dynamic enough.*  
(Abigail)

Through the pain experience it appeared that some participants' sense of self began to collapse. Evelyn stated, when she talked about having to prioritise

differently from others her age “[That’s] not something you expect doing, particularly when otherwise I feel quite fit and healthy”. The unexpectedness also resonated with Danielle’s experience. She described how pain led to a substantial change in her life and a loss of her sense of self. As a physiotherapist, she exemplifies the fact this can happen to anyone, regardless of personal background, education or knowledge.

*I’ve always been very fit,  
very able,  
it was a blow to my sense of self.  
My body let me down hugely.  
That whole sense of disability hit me  
very, very hard,  
I was not ready for it.*

*When I was still unwell  
I catastrophised,  
thought I’d need surgery.  
In pain you are lost,  
no matter who you are!*

*(Danielle)*

### The pain battle

The hunt for coping strategies was often described as a process of trial and error, which was strongly connected to the individual’s beliefs about the causes of pain. As a result of failed interventions or a loss of previous successful strategies some experienced further disappointment. For others, new beliefs and strategies appeared to evolve leading to a different understanding of the cause of pain and a change from purely biomedical, perceived body-centred to additional emotional coping strategies. For Frank it almost seemed that failed biomedical - oriented interventions guided him towards a biopsychosocial understanding of pain.

*The pharmaceutical route  
didn't work,  
the surgical route  
didn't work,  
so what else was I left with?  
I had to buy into this.*

*(Frank)*

Management strategies related to physical activity were dominant in all accounts. However, activities varied quite significantly. Walking, swimming, dancing, core stability and general exercises were only a few examples mentioned by participants. However, there was variation in how these were experienced, for example, while some found relief through core exercises, others found them “*dreadfully dull*” or not helpful at all.

*Pilates had a beneficial effect,  
quite quickly my core felt stronger  
and my back felt better supported.*

*(Caroline)*

*I never do that anymore.  
I had the perfect set of abs  
but the most chronic back pain ever.*

*As taught by certain physios,  
I built and built a solid core  
to protect the spine  
which sends the wrong signals to the brain.*

*Rubbish!*

*(Frank)*

Frank's description implied that it was not the core stability exercises as such, but the associated message given by healthcare professionals to protect the spine to avoid “*micro-movement*”, that led to fear-avoidance behaviour.



Participants' accounts illuminated the value of their evolving understanding of the entwinement between mind and body and the influence of this on their wellbeing. Danielle expressed the meaning of her personal struggle when the healing process took longer than she expected, and she reported of catastrophising. Yet, after a reassuring conversation with one of her colleagues she felt better immediately:

*I was beating myself up  
for not being better after six weeks.  
“It takes time” my colleague said  
and immediately I felt better.  
These tiny things actually had a huge impact.*  
*(Danielle)*

This evolving conception of pain was conveyed in the accounts by moving away from what they perceived as primarily “physically” related coping strategies. For Frank, multidimensional pain education was pivotal to his changing understanding in which his evolving conception of mind and body connection was the starting point; thereafter he adopted other self-taught strategies such as meditation, sleep hygiene and nutrition.

<i>Anxiety fuels pain: the things I hear, I see, I smell and can be damp down by things that are safe, pleasurable, adding value to my life.</i>	<i>Once explain pain was given to me, everything else followed, like a domino effect.</i>
	<i>(Frank)</i>

Most participants described varied mindful strategies as meaningful in helping them to cope with persistent pain. Meditation helped Frank better manage his fear and anxiety, which he attributed to pain and previous traumatic events in his

life. *“I’m a big fan now, and I never used to be, of mindfulness, meditation and breathing.”* Caroline, a psychotherapist, used work skills such as cognitive behavioural therapy, whereas, for Evelyn, breathing techniques from yoga helped her to control pain.

*Yoga gives me time to stop,  
to breathe.  
I’ve learned different types of breathing,  
which helps when I’m in pain,  
particularly out in public.*

*(Evelyn)*

There were hurdles along participants’ self-management journey, which were characterised by feelings of uncertainty. Some participants described the challenges experienced emotionally when previous successful strategies suddenly failed. They conveyed a sense of uncertainty in which concerns about the future rose up, which required them to consider different ways to manage this new situation.

*What’s next?  
I am a bit worried,  
it was my go-to.  
That’s the mental side,  
the coping side,  
stopping those thoughts.*

*I’m thinking of a career change,  
not having to sit all day.*

*Don’t know yet.*

*(Evelyn)*

This uncertainty resonated with Ben's story which appeared to hide a sense of a dissonance. He described having an "endorphin rush" when he is active which makes him feel good. But he also expressed fear of doing too much which might exacerbate the pain. This seemed to leave him with uncertainty about his current exercise regime.

*I do a few more things,  
pushing myself a bit more.*

*When I run*

*I feel high,*

*when I play table tennis*

*I feel high.*

*I enjoy physical activity,*

*the feeling of well-being,*

*the power in my body.*

*But pain is always in the back of my mind,*

*I am traumatised by it.*

*I am afraid of doing too much.*

*After a run I had pain this week,*

*I don't know if I'll do another run,*

*I also put the brakes on table tennis now,*

*I just don't want to take that risk.*

*I'm scared*

*(Ben)*

*I'm a bit more adventurous.*

Accounts also conveyed the challenges to maintain social contacts and work requirements. Some participants expressed having to plan activities and appointments precisely throughout the day and week at the expense of being spontaneous. Evelyn expressed dissonance, on the one hand she recognised the danger of social isolation but expressed uncertainty as to whether the required planning effort prior to social engagements will be worth it in the end.

*Coping means planning everything,  
the whole week is planned around one evening  
without knowing if it's worth it,  
but otherwise I don't do anything.*

*That's the danger with any chronic condition,  
it takes over,  
it controls you  
if you are not careful.*

*(Evelyn)*

In addition to the logistical challenges of engaging in social situations, participants also conveyed the challenges of navigating the complexity of interacting with others who do not understand their experience. Participants' accounts illuminated the perceived importance of hiding symptoms in order to avoid social judgement. In Danielle's account, it also seemed that her understanding of her professional identity as a physiotherapist prompted her to hide her symptoms.

*Coping means hiding it!  
I pride myself on nobody knowing,  
nobody knows here about  
the disc lesion, the foot drop,  
that's my history.*

*Why I am hiding it?  
It's part of the professional identity,  
it's embarrassing  
having backache like our patients.*

*I am distancing myself  
not to be seen as "patient-like",  
I don't want people to know me  
as disabled,  
as exaggerating.*

*(Danielle)*

Evelyn articulated a strategy she uses to deal with the impact on her mood caused by others' comments. She uses different replies depending on how well she knows the other person.

*I could get upset by others' comments,  
so I respond differently to different people,  
I give them a  
short, medium or long response  
depending on how well they know me.*

*(Evelyn)*

She acknowledged that *others* do not consciously want to upset her and that they sympathise; they just do not or cannot understand her struggle. There is a sense by which if you have not experienced persistent pain yourself you cannot possibly understand. To cope in these situations she started to ask directly for help, to explicitly make them aware. However, as she pointed out, asking for help is difficult because it implies an acceptance that pain is not going away.

*Now I ask my friends to wait  
and I don't get upset about it anymore.  
My symptoms fluctuate so much  
they just don't know.  
It's not a lack of sympathy.*

*When you ask for help  
you're admitting,  
accepting,  
that it's here,  
that it's not going away.*

*(Evelyn)*

### A new normal

Despite the difficulties of accepting the ongoing presence of pain, there was a sense of acceptance being pivotal in participants' journey to finding a new normal. This was meaningfully related to time to trial different strategies and, for some participants, to develop a more multidimensional understanding of pain. Time was also essential for some to return to meaningful activities and to develop a trust in their body and their intuition. Most participants described specific coping strategies that came to the fore as they tried different activities and started to trust their body and in their experience.

*It was just experience,  
the swimming, the jacuzzi,  
no one recommended it,  
it just felt really good.*

*(Ben)*

Ben's experience resonated with Evelyn's description when she explained that "listening to (my) body is the biggest thing that I've learned." Others revealed similar experiences where no one recommended a particular exercise but they just "gravitated" towards it or knew their body and what they needed and trusted their intuition.

*I had to get the work done,  
lying on the floor,  
taking medication  
wasn't an option any more.*

*I know how my body works,  
what I want from it.  
It was not being able to walk or cycle  
that sort of drove me to do more.*

*That's when I adapted:  
no one said "think about exercising"  
I just gravitated towards it.*

*(Caroline)*

*I did a lot of core stability  
and found it dreadfully dull,  
my core was better,  
but I couldn't walk any further,  
the treatment was very narrow,  
back-focused.*

*But my back?  
It is what it is.*

*(Danielle)*

Danielle expressed a sense of acceptance that the pain was there to stay: "But my back? It is what it is". Yet she wanted to return to meaningful activities, despite the pain. This resonated with Frank, who was able to return to football despite the pain.

*Rather than fight pain  
the solution was almost acceptance.  
So, I got out more,  
doing things I used to do and love  
and it started to work.*

*(Frank)*

Evelyn implied that the acceptance of pain was not easy and a gradual process. She needed time to try different treatments to realise that there is no fix and that she had to let go of that *old normal* in order to find and accept a *new normal*. In her opinion this was essential in order to move forwards and *live* again.

*After years and things I've tried,  
gradually I had to accept  
that this is not to be fixed,  
that I have to find a way to manage it  
the best I can.*

*It is hard,  
but unless you get to that point  
you can't move forwards and  
live a life with pain.*

*(Evelyn)*

*“Accept letting go of that old normal,  
look at a new normal instead.”*

*Five years later I get what it means:  
it's not worse,  
it's just different,  
and it has gradually become normal for me.*

However, not all participants seemed to have moved “forwards” and gained a sense of acceptance even over longer periods of time. Despite having experienced pain for 35 years, Abigail appeared still to be caught somewhere between *the loss of a sense of self* and *the pain battle*.

*It's negative really,  
some people accept,  
maybe I am just not accepting.*

*I've got pain and I hate it,  
I'm angry and pissed off,  
I feel stupid and peeved  
not to have managed the pain better,  
I'm ageing and I don't want to age and  
I've socially withdrawn.*

*(Abigail)*

Despite accepting and coping with the presence of pain, other accounts also illuminated ongoing struggles, mainly with the remaining anxiety caused by pain. This was meaningfully related to the unpredictable pain, uncertainty and fear of “*regressing into the old world*”. But for some participants, like Frank, this did not mean “not coping”. Instead, as Danielle expressed, the fear and the panic was seen as part of the *new me, a new normal*. Coping meant gaining a sense of control over the panic which had become part of normality and therefore not unexpected any more.

*I'm still in pain,  
I still struggle,  
I still have anxiety,  
but I still cope.*

*(Frank)*

*I try to manage the panics that I feel  
by seeing the pain slightly differently,  
it's like a part of me,  
I'm trying to embrace it,  
like the new me.*

*(Danielle)*

In some accounts there was a sense that a wider learning has taken place out of this traumatic experience, not only involving their understanding of pain but also a self-understanding and a consideration of others. Ben reported that he is now more empathetic and Frank conveyed that he uses his experience to help not only others with PLBP but also healthcare professionals, which is valuable to him “*because I am giving something back*”. Danielle reached an understanding of



increased pain as “a warning sign” which prompted her to change her lifestyle and maintain a better work/life balance.

*I have a much better work/life balance,  
I use my bad back as a flag,  
it tells me when my life is not right,  
it hurts more when I'm sitting too much  
and it makes me to cycle to work,  
like: “You want me to go away?  
Well DO something!”*

*(Danielle)*

## DISCUSSION

The lived experience of persons who self-identify as “coping” with PLBP was conveyed as a journey with three stages of meaning: the loss of a sense of self leading to the pain battle and onwards towards a new normal. However, these stages were not clearly defined, and a progression and regression between the stages was conveyed in participants’ accounts. The journey elucidated how life changing PLBP can be, not only affecting participants’ bodies but their entire lifeworld, which resonated with other studies exploring the experience of PLBP (Bunzli et al, 2013; MacNeela et al, 2015; Stensland and Sanders, 2018).

Lifeworld is increasingly used in healthcare research and is divided into five different dimensions, which are strongly interrelated and inter-twined (Todres, Galvin, Dahlberg, 2007). The following discussion will reflect on how the different dimensions of lifeworld resonated with participants’ journey towards coping. Mood, embodiment, inter-subjectivity and temporality dominated participants’ accounts and are further illuminated below. Spatiality, which refers to the meaningful places and things in a person’s environment (Todres, Galvin,

Dahlberg, 2007), emerged but was less pervasive in this study.

### Mood

The meaningful relationship between PLBP and persons' mood was conveyed in all accounts and in all three stages. In lifeworld, mood is related to all dimensions, as lived experience brings emotions to the foreground (Todres, Galvin, Dahlberg, 2007). Anxiety, depression and low mood expressed in the first stage resonated with other literature exploring the experience of PLBP (Bailly et al, 2015; Corbett, Foster, Ong, 2007; MacNeela et al, 2015; Singh et al, 2018). In the current study, participants' accounts suggested that anxiety and fear of pain remained meaningful and an existential challenge even in the latter stage. However, some accounts of those who appeared to have moved towards a new normal, conveyed that they have found strategies to regain some control over their thoughts and feelings and embraced these emotions as a part of their new self. The strategies varied between participants and for some were linked to a development of a more multidimensional understanding of pain. The development in some participants' understanding reflects the paradigm shift that has occurred in western healthcare, whereby understanding has evolved from a biomedical to a biopsychosocial model and latterly towards a more holistic understanding (Daluiso-King and Hebron, 2020).

This new understanding of pain in some of the accounts conveyed a change in "being" and participants' journey towards psychological flexibility and acceptance (McCracken and Morley, 2014). The concept of psychological flexibility aims not to reduce pain or negative emotions like fear but rather to cultivate a conscious awareness of these emotions so that they do not inhibit

behaviour or the movement towards valuable goals (McCracken and Morley, 2014). This was illuminated in Frank's account when he described returning to his beloved football despite ongoing anxiety and pain. Participants' stories conveyed how meaningful acceptance of pain was to "live" again. Conversely difficulties in finding acceptance were expressed by Abigail who reflected that the lack of acceptance might be the reason of her ongoing struggle. Her challenges with acceptance and the futility of struggling against the pain resonated with previous literature (Bunzli et al, 2013; MacNeela et al, 2015).

### Embodiment

Intertwined with the influence of pain on mood, participants' accounts illuminated how pain led to bodily changes, the feeling of 'disability' and the inability to engage with meaningful activities. Embodiment refers to "the lived body; one that is not best described by chemicals and neurones but by how we bodily live in meaningful ways in relation to the world and others" (Todres, Galvin, Dahlberg, 2007, p. 57). Meaning that human beings can never free themselves from their body, never "stand outside their subjective bodies" (Dahlberg, Dahlberg, Nyström, 2008, p. 41). The body is the vehicle to access the world and through the subjective bodily experience the world becomes meaningful (Dahlberg, Dahlberg, Nyström, 2008, p. 41). The influence of pain on participants' subjective body may explain the reported loss in their sense of self which resonated with the literature exploring the experiences of other persons suffering with PLBP (Bunzli et al, 2013; Snelgrove, Edwards, Liossi, 2013; Stensland and Sanders, 2018; Toye and Barker, 2012).

When life-changes such as the development of pain appear gradually,

they give the person time to adapt routines, behaviour and interactions with others. But when changes occur suddenly or are of a significant nature, adaptation becomes difficult or impossible (Engman, 2019), potentially leading to “biographic disruption” (Bury, 1982). This resonated with Danielle’s experience when she expressed how suddenly and unexpectedly pain entered her life, not giving her time to adapt and as such, her taken-for-granted lifeworld suddenly “becomes a burden of conscious and deliberate action” (Bury, 1982, p. 176). This burden may drive the sufferer to mobilise resources (Bury, 1992) which echoed participants’ stories. Their testimonies illuminated a sense of chaos, a battle with personal beliefs about the cause of pain, involving a trial and error of strategies. This resonated with Arthur Frank’s concept of chaos narrative, an anxiety-provoking story with a plot where life never gets better and the life lived is not a “proper” life. He described chaos as a continued yet unsuccessful attempt of the sufferer to regain lost control (Frank, 1998). The concept of chaos also echoed that reported by Bullington et al. (2003), in which chaos was described as a blurred and confused stage wherein the sufferer attempts to regain control.

To regain control, all participants described perceived body-centred strategies. These strategies, however, diverged within accounts as they were differently experienced in terms of their effectiveness. This echoed the literature which was unable to detect a superior physical coping strategy (Vanti et al, 2019; Wang et al, 2012). The development of coping strategies was described as a trial and error process of both, directed and self-directed strategies. Participants conveyed the importance of self-directed learning and the development of trust in their own personal experience and intuition. Modern

healthcare advocates to involve sufferers' opinions and experiences into the treatment decision. This led to a responsibility shift in the care-seeker/care-taker relationship towards the person seeking care, hence self-directed learning has become more important in recent decades (King, 2014). It was argued that the responsibility shift is down to the increased value of the care-seekers' testimony (Buchman, Ho, Goldberg, 2017). Others say it is a result of cut backs in healthcare, legal claims and political interests (King, 2014). This power and responsibility shift, however, is still unfamiliar for some (Taylor, 2009) and to process new information requires literacy and research skills, which some care-seekers from poor educational backgrounds and learning difficulties might struggle with in a context of only limited external support (King, 2014). Moreover, as Danielle the physiotherapist explained, pain may interfere with the rational thought process, which makes absorbing new information more challenging "no matter who you are". This challenge in processing new information in the presence of pain has been reported elsewhere (Corbett, Foster, Ong, 2007). In order to prepare society for the responsibility shift, healthcare providers will have to offer more appropriate educational support in the future (King, 2014) and health education in schools may need to be adjusted to meet the new demands in healthcare early on.

A strong interconnectedness between embodiment and intersubjectivity was seen in some accounts when the perceived body-centred strategies not only seemed to positively influence participants' bodily experience, but also led to a positive change in their mood and personal relationships, conveying the meaning of connecting with others through physical activities. However, despite the positive influence of perceived body-centred strategies on personal

relationships for some, a number of participants conveyed the need to develop specific coping strategies to restore their relationships with others.

### Inter-subjectivity

In the current study, participants conveyed a meaningful change in personal relationships leading some to become socially withdrawn and isolated at the beginning of their journey. As Abigail experienced: “I withdrew socially (...) but others have also withdrawn from me”. Inter-subjectivity describes how human beings interact, live with, and relate themselves to others (Todres, Galvin, Dahlberg, 2007). These relationships are important as we use *others* to reference ourselves (Todres, Galvin, Dahlberg, 2007), which influences our sense of self (Ashworth, 2016). Previous qualitative research has illuminated persistent pain sufferers experience of being *othered* (Lennox Thomson 2019, pp. 17, 28-30) which correlates with some accounts presented here. In the literature, *othering* or being *othered* is described as a process that labels persons as different from what society deems to be “mainstream” and consequently excludes the *other* (Johnson et al, 2004).

The experience of being othered might explain why the third master-theme, a new normal, emerged from participants’ accounts. The definition of “normality” or “normal”, is strongly related to what society defines as “abnormal” (Jovanoski and Rustemi, 2021). Finding a new normality was previously expressed and seen as important in order to live well with chronic conditions (Olano-Lizarraga, Wallström, Martín-Martín, Wolf, 2022). In the current study the term “a” new normal was chosen as it implies fluidity, changeability, or fragility, in

contrast to “the” new normal, which suggests a certainty and stability which does not correlate with the remaining uncertainty in participants’ accounts.

Othering is also strongly linked to stigmatization and labelling, and chronically ill persons often experiencing stigmatization and labeling as they diverge from societies’ norm (Grinker, 2021). This can be caused by persons in the wider society and - even if unintentionally - due to the behaviour of healthcare clinicians’ towards persistent pain sufferers (Lennox Thompson, 2019, pp. 28-30). Qualitative studies have illuminated PLBP experience of stigmatization and labeling (Bunzli et al, 2013; MacNeela et al, 2015). This experience of doubt and a lack of acknowledgment of pain was also expressed in the current accounts and resonated with Elaine Scarry, who says: “to have great pain is to have certainty; to hear that another person has pain is to have doubt.” (Scarry, 1985, p. 7). In contrast, receiving others’ acknowledgement of pain and symptoms was positively perceived by participants in this study. Similar findings were reported by Bailly et al. (2015) when PLBP sufferers reported positive experiences when family and friends provided assistance by showing understanding and being able to listen and to motivate.

To restore and cope with intersubjective changes different strategies were reported by some participants in this study. For Danielle, her perception that she was facing disapproval at work led her to hide her symptoms. Evelyn’s account also seemed to reveal an element of “hiding” information by providing only short or medium answers to some people in her community. Hiding pain or symptoms has been expressed by other chronically ill persons (Almegewly, Gould, Anstey, 2019; Neville-Jan, 2003). Evelyn also appeared to try to rationalise others’

behaviour by reminding herself of the complexity of pain and therefore the inability for others to understand her situation. By doing so Evelyn seems to put herself in non-sufferers shoes. This method is described in the literature as “role-taking” and “world travelling” and was suggested by Roberts and Schiavenato (2017) to be applied in nursing as a form of inclusionary othering. In this context, however, the authors suggested that the nurse or healthcare professional is taking on the role of the sufferer to develop an understanding and empathy for the person in pain and as a result prevent othering. These forms of inclusionary othering were initially described by Canales (2000). Lennox Thompson, a female academic and sufferer of fibromyalgia, discussed in her autoethnography another concept to prevent othering: the concept of “charity”. This concept was first described by Brons (2015). He suggested seeing persons’ actions and behaviour as reasonable even if at first it is not possible to discover the *true* underlying reason. This *charitable interpretation* on others’ actions may invoke a reflection of one’s own personal preconceptions and assumptions about the reasons leading others, like pain sufferers, to their actions (Brons, 2015). Lennox Thompson (2019, p. 29) suggests that this concept could be applied in healthcare but also in wider society to prevent othering. If healthcare professionals and the wider society are able to move towards a more inclusive practice of othering by “taking on the role of the other”, “travelling to the world of the other” or applying a “charitable interpretation” on others behaviour, this may reduce the battle to retain the sense of self experienced by persons with persistent pain.

### Temporality

The meaning of time and its relationship with coping was illuminated in most



accounts and throughout their journey towards coping. Participants' descriptions conveyed a strong temporal component, revealing that travelling through chaos, with its trial-and-error strategies in the attempt to restructure the different dimensions of their lifeworld and the process of acceptance and self-trust, required time. For some participants this took many years and there was a sense that this was experienced longer than actual clock time. Henri Bergson, a French philosopher has argued that humans are able to experience time in two different ways, chronological time and a subjective experience of time, how time is lived through. The latter is influenced by past memories, experience and feelings. If those experiences are of positive nature, the latter is likely experienced as longer (Moravec, 2020). Thus, Bergson's argumentation might explain why for participants the perception of time appeared prolonged during this difficult journey towards coping with PLBP.

The current literature suggests that healthcare professionals are gradually reconceptualizing the management of persons with PLBP towards one of supported and guided self-management, aiming to provide a better, more meaningful life for sufferers. Accounts here illuminated the ability for persons to find new meaning despite PLBP and the authors' hope is that this study will be able to further contribute to the vision of better care for those seeking help. As time appears to play an overriding role towards coping, healthcare providers and policy makers may need to question if the current operating framework is suitable to provide time-intense, person-centred, empathic healthcare. The current provided time frames in clinics suggest a remaining in a biomedical understanding of illness. This can leave both therapists and persons seeking care unfulfilled due to a lack of time to sit with the person in need and to support

them through the period of chaos and trial and error.

### Clinical implication

We are embodied beings who live through our bodies and thus pain invades different dimensions of human life. In order to guide persons with PLBP on their journey to coping with PLBP therapists should allow space for them to tell their story, seek to understand their “lifeworld” and legitimize their experience. Only those clinicians willing to become witness to the story and provide empathetic care can help others to escape the chaos. Persons whose chaos story is not legitimised can receive care but cannot be recipients of empathic care (Frank, 1995). It is the researchers’ hope that the poetic excerpts encourage clinicians to pause, and empathically engage with these participants’ accounts as well as those of persons receiving their care. To “sit with” persistent pain sufferers takes time, often several years, as persons engage in a battle with own beliefs and learn to develop their own management strategies. Clinicians may recognise that in the trial-and-error approach towards learning to “cope” with PLBP, some persons may need to explore biomedical strategies before, in time, they are able to engage in a more multidimensional understanding of pain. Being able to sit with persons “suffering” as they navigate their journey towards coping, and hopefully with time, find a way through the chaos to a place of human flourishing whilst living with PLBP. Policy makers and healthcare providers may have to question how time is best allocated within and between appointments to provide best care. Offering greater time with less frequency and over a longer period of time may better align with persons’ journey towards coping.

We also hope that participants' poems might be shared with other persons living with PLBP to create a feeling of belonging and to provide a context in which conversations about feelings, thoughts, emotions and experiences can be openly shared which can then help clinicians to understand the sufferers' lifeworld. These findings suggest that coping with changes to interpersonal relationships are important. With this in mind, clinicians may explore the influence of others on persons' experiences and, through discussion, consider whether significant others might be involved in the clinical encounter and management plan. The poems provided may also help non-sufferers to understand the lifeworld of a person with PLBP and encourage inclusionary behaviour.

### CONCLUSION

This study revealed the journey towards coping with PLBP through three master themes: the loss of a sense of self, the pain battle and the new normal. Acceptance, self-trust and the confidence to explore different strategies independently appeared to be important on the journey towards a new normal. This seemed dependent on the passage of time, with some participants taking years to learn to cope with their situation. Due to the subjective bodily experience of pain, coping strategies need to address a person's entire lifeworld. These findings illuminated the importance of empathetic, understanding clinicians who validated persons' individual stories. The significance of others in a person's journey towards coping suggests that there could be value in healthcare professionals helping them to explore the influence of their families and society on their experiences. Lastly, health professionals

might consider mechanisms for educating the wider healthy population about the complexity of pain to make it more socially understood and accepted.

Declaration of interest

The authors report there are no competing interests to declare.

## REFERENCES

- Almegewly W, Gould D, Anstey S 2019 Hidden voices: an interpretative phenomenological analysis of the experience of surviving breast cancer in Saudi Arabia. *Journal of Research in Nursing* 24: 122-132.
- Ashworth PD 2016 The lifeworld - enriching qualitative evidence. *Qualitative Research in Psychology* 13: 20-32.
- Bailly F, Foltz V, Rozenberg S, Fautrel B, Gossec L 2015 The impact of chronic low back pain is partly related to loss of social role: A qualitative study. *Joint Bone Spine* 82: 437-441.
- Balagué F, Mannion AF, Pellisé F, Cedraschi C 2012 Non-specific low back pain. *Lancet* 379: 482-491.
- Bevan MT 2014 A method of phenomenological interviewing. *Qualitative Health Research* 24: 136–144.
- Blank A, Finlay L, Prior S 2016 The lived experience of people with mental health and substance misuse problems: Dimensions of belonging. *The British Journal of Occupational Therapy* 79: 434-441.
- Braun V, Clarke V 2013 *Successful Qualitative Research: A Practical Guide for Beginners*, p. 285. London: SAGE.
- Brons L 2015 Othering, An analysis. *Transcience, a Journal of Global Studies* 6: 69-90.
- Buchman DZ, Ho A, Goldberg DS 2017 Investigating trust, expertise, and epistemic injustice in chronic pain. *Journal of Bioethical Inquiry* 14: 31-42.
- Bullington J, Nordemar R, Nordemar K, & Sjöström-Flanagan C 2003 Meaning out of chaos: a way to understand chronic pain. *Scandinavian Journal of Caring Sciences* 17: 325-331.
- Bunzli S, Watkins R, Smith A, Schütze R, O'Sullivan P 2013 Lives on hold: a qualitative synthesis exploring the experience of chronic low-back pain. *The Clinical Journal of Pain* 29: 907-916.
- Bury M 1982 Chronic illness as biographical disruption. *Sociology of Health & Illness* 4: 167-182.
- Canales MK 2000 Othering: toward an understanding of difference. *ANS Advances in Nursing Science* 22: 16-31.

- Converse M 2012 Philosophy of phenomenology: How understanding aids research. *Nurse Researcher* 20: 28-32.
- Corbett M, Foster NE, Ong BN 2007 Living with low back pain—Stories of hope and despair. *Social Science & Medicine* (1982) 65: 1584-1594.
- Creswell JW, Poth, CN 2017 *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. 4<sup>th</sup> edition, p. 161. SAGE publication.
- Dahlberg K, Dahlberg H, Nyström M 2008 *Reflective Lifeworld Research* (2nd ed.), pp. 41, 73, 134-137, 175-176. Studentlitteratur.
- Daluiso-King G, Hebron C 2020 Is the biopsychosocial model in musculoskeletal physiotherapy adequate? An evolutionary concept analysis. *Physiotherapy Theory and Practice* 38: 1-17.
- de Vries HJ, Brouwer S, Groothoff JW 2011 Staying at work with chronic nonspecific musculoskeletal pain: a qualitative study of workers' experiences. *BMC Musculoskeletal Disorders* 12: 126
- Deyo RA, Weinstein JN 2001 Low back pain. *The New England Journal of Medicine* 344: 363-370.
- Dima A, Lewith, GT, Little P, Moss-Morris R, Foster NE, Bishop FL 2013 Identifying patients' beliefs about treatments for chronic low back pain in primary care: a focus group study. *British Journal of General Practice*, 63: e490-498.
- Engman A 2019 Embodiment and the foundation of biographical disruption. *Social Science & Medicine* (1982) 225: 120-127.
- Finlay L 2009 Debating phenomenological research methods. *Phenomenology & Practice* 3: 6-25.
- Finlay L 2014. Engaging phenomenological analysis. *Qualitative Research in Psychology* 11: 121-141.
- Fitzpatrick N, Finlay L 2008 "Frustrating disability": The lived experience of coping with the rehabilitation phase following flexor tendon surgery. *International Journal of Qualitative Studies on Health and Well-being* 3: 143-154.
- Frank AW 1998 Just listening: Narrative and deep illness. *Families, Systems, & Health*, 16: 197–212.

- Grinker RR 2021 *Nobody's Normal: How Culture Created the Stigma of Mental Illness*. W. W. Norton & Company.
- Hutting N, Oswald W, Staal, JB, Heerkens, YF 2020 Self-management support for people with non-specific low back pain: A qualitative survey among physiotherapists and exercise therapists. *Musculoskeletal Science and Practice* 50: <https://doi.org/10.1016/j.msksp.2020.102269> (Accessed: 08 February 2021).
- Johnson JL, Bottorff JL, Browne AJ, Grewal S, Hilton, BA, Clarke H 2004 Othering and being othered in the context of health care services. *Health Communication* 16: 253-271.
- Jovanoski A, Rustemi A 2021 Theory of labeling: Contemporary concepts of the sociological understanding of deviance. *International Journal of Scientific and Engineering Research* 607 - 615.
- King KP 2014 A journey with chronic pain: Self-directed learning as survival. *New horizons in Adult Education & Human Resource Development* 26: 5-18.
- Kvale S, Brinkmann S 2009 *InterViews: Learning the Craft of Qualitative Research Interviewing* (2nd ed.), pp. 30-31, 128, 135, 210. Sage Publications.
- Lennox Thompson B 2019 After the tango in the doorway: An autoethnography of living with persistent pain. In: van Rysewyk, S. (eds) *Meanings of Pain*, pp. 17-35. Springer, Cham.
- Lennox Thompson B, Gage J, Kirk R 2020 Living well with chronic pain: a classical grounded theory. *Disability and Rehabilitation* 42: 1141–1152.
- MacNeela P, Doyle C, O'Gorman D, Ruane N, McGuire BE 2015 Experiences of chronic low back pain: a meta-ethnography of qualitative research. *Health Psychology Review* 9: 63-82.
- Malterud K, Siersma VD, Guassora AD 2016 Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research* 26: 1753–1760.
- Matua GA, Van Der Wal DM 2015 Differentiating between descriptive and interpretive phenomenological research approaches. *Nurse Researcher* 22: 22-27.

- McCracken LM, Morley S 2014 The psychological flexibility model: a basis for integration and progress in psychological approaches to chronic pain management. *The Journal of Pain* 15: 221-234.
- Meroni R, Piscitelli D, Ravasio C, Vanti C, Bertozzi L, De Vito G, Perin C, Guccione AA, Cerri CG, Pillastrini P 2021 Evidence for managing chronic low back pain in primary care: a review of recommendations from high-quality clinical practice guidelines. *Disability and Rehabilitation* 43: 1029–1043.
- Meucci RD, Fassa AG, Faria NM 2015 Prevalence of chronic low back pain: systematic review. *Revista de Saude Publica* 49.  
<https://doi.org/10.1590/s0034-8910.2015049005874> (Accessed: 03 March 2021).
- Mittelmark MB, Bauer GF 2022 Salutogenesis as a theory, as an orientation and as the sense of coherence. In: *The Handbook of Salutogenesis*, pp. 11–17. Springer, Cham.
- Moravec M 2020 A philosophical idea that can help us understand why time is moving slowly during the pandemic. QRUIS. <https://qrius.com/a-philosophical-idea-that-can-help-us-understand-why-time-is-moving-slowly-during-the-pandemic/> (Accessed: 28 December 2021).
- Neubauer BE, Witkop CT, Varpio L 2019 How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education* 8: 90-97.
- Neville-Jan A 2003 Encounters in a world of pain: An autoethnography. *The American Journal of Occupational Therapy* 57: 88-98.
- Olano-Lizarraga M, Wallström S, Martín-Martín J, Wolf A 2022 Causes, experiences and consequences of the impact of chronic heart failure on the person's social dimension: A scoping review. *Health & Social Care in the Community*: 30: e842– e858.
- Osborn M, Smith JA 2006 Living with a body separate from the self. The experience of the body in chronic benign low back pain: an interpretative phenomenological analysis. *Scandinavian Journal of Caring Science* 20: 216-222.

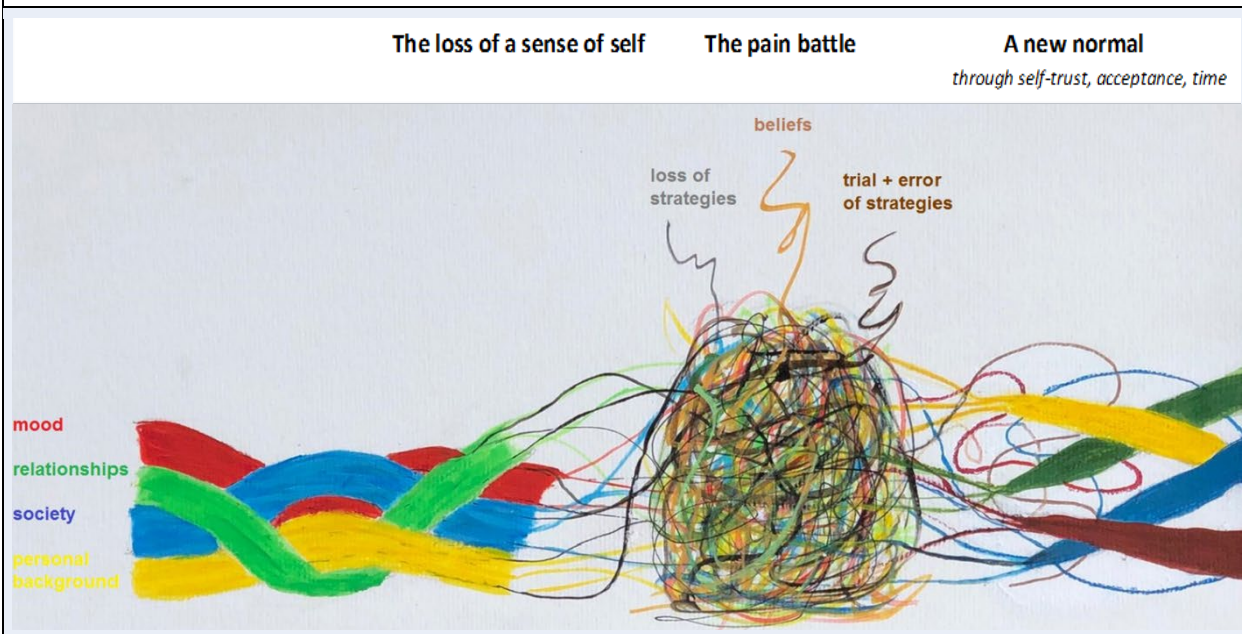


- Owens JE, Menard M, Plews-Ogan M, Calhoun LG, Ardelt M 2016 Stories of Growth and Wisdom: A Mixed-Methods Study of People Living Well with Pain. *Global Advances in Health and Medicine* 5:16–28.
- Roberts MLA, Schiavenato M 2017 Othering in the nursing context: A concept analysis. *Nursing Open* 4: 174-181.
- Scarry E 1985 *The Body in Pain: The Making and Unmaking of the World* (New ed.), p. 7. Oxford University Press.
- Singh G, Newton C, O’Sullivan K, Soundy A, Heneghan NR 2018 Exploring the lived experience and chronic low back pain beliefs of English-speaking Punjabi and white British people: a qualitative study within the NHS. *BMJ Open* 8: e020108-e020108.
- Smith JA, Osborn M 2007 Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health* 22: 517-534.
- Snelgrove S, Edwards S, Lioffi C 2013 A longitudinal study of patients' experiences of chronic low back pain using interpretative phenomenological analysis: changes and consistencies. *Psychology & Health* 28: 121-138.
- Stenner R, Mitchell T, Palmer S 2016 The role of philosophical hermeneutics in contributing to an understanding of physiotherapy practice: A reflexive illustration. *Physiotherapy* 103: 330-334.
- Stensland ML, Sanders S 2018 "It has changed my whole life": The systemic implications of chronic low back pain among older adults. *Journal of Gerontological Social Work* 61: 129-150.
- Taylor K 2009 Paternalism, participation and partnership - the evolution of patient centeredness in the consultation. *Patient Education Counseling* 74: 150-155.
- Todres L, Galvin K, Dahlberg K 2007 Lifeworld-led healthcare: Revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy* 10: 53-63.
- Todres L 2008 Being with that: the relevance of embodied understanding for practice. *Qualitative Health Research* 18: 1566–1573.

- Toye F, Barker K 2012 'I can't see any reason for stopping doing anything, but I might have to do it differently'--restoring hope to patients with persistent non-specific low back pain--a qualitative study. *Disability and Rehabilitation* 34: 894-903.
- Toye F, Seers K, Allcock N, Briggs M, Carr E, Andrews J, Barker K 2013 Patients' experiences of chronic non-malignant musculoskeletal pain: a qualitative systematic review. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners* 63: e829-e841.
- van Griensven H 2015 Patients' experiences of living with persistent back pain. *International Journal of Osteopathic Medicine* 19: 44-49.
- van Manen M 2014 *Phenomenology of Practice: Meaning-Giving Methods in Phenomenological Research and Writing (Vol. 13)*, pp. 220, 249-267, 347, 367. Left Coast Press.
- Vanti C, Andreatta S, Borghi S, Guccione AA, Pillastrini P, Bertozzi L 2019 The effectiveness of walking versus exercise on pain and function in chronic low back pain: a systematic review and meta-analysis of randomized trials. *Disability and Rehabilitation* 41: 622–632.
- Wang XQ, Zheng JJ, Yu ZW, Bi X, Lou SJ, Liu J, Cai B, Hua YH, Wu M, Wei M, Shen HM, et al. 2012 A meta-analysis of core stability exercise versus general exercise for chronic low back pain. *PLoS ONE* 7: e52082.
- Wu A, March L, Zheng X, Huang J, Wang X, Zhao J, Blyth FM, Smith E, Buchbinder R, Hoy D 2020 Global low back pain prevalence and years lived with disability from 1990 to 2017: estimates from the Global Burden of Disease Study 2017. *Annals of Translational Medicine* 8: 299.

<b>Table 1: Characteristics of study participants</b>						
Pseudonym / gender	Age	Years of pain	Distribution of pain	Previous treatment interventions	Employment	Occupation
Abigail (Female)	69	35	Localised LBP	Medication, pain management course, physiotherapy (1:1 and group), acupuncture, chiropractor	Retired	Public sector
Ben (Male)	59	12	Previously LBP, now mainly radiating leg pain	Medicating, physiotherapy (1:1 and group), injection, yoga, pilates	Full-time	Coach/Teacher
Caroline (Female)	57	40	Localised LBP	Medication, injections, osteopath, physiotherapy, chiropractor, acupuncture	Part-time	Psychotherapist
Danielle (Female)	57	7	LBP and radiating leg pain	Medication, physiotherapy, sports therapy	Full time	Physiotherapist
Evelyn (Female)	50	10	Localised LBP	Medication, radio frequency denervation, medial branch blocks, physiotherapy, osteopathy, chiropractor, yoga, pilates, hydrotherapy	Full time	Financial service
Frank (Male)	55	7	Now mainly localised LBP, previously also radiating leg pain	Medication, 2 operations for LBP, physiotherapy, osteopathy, chiropractor, alternative treatment	Retired	Emergency services
LBP = low back pain						

## Drawing 1: The journey towards coping: master-themes and sub-themes



The colored threads represent the sub-themes which together form the sense of self. Pain, symbolized by the black fibres infiltrates the sense of self, causing the loss of a sense of self, the first master-theme. This leads to the pain battle, the second master-theme where personal beliefs about the cause of pain, the trial-and-error process of new management strategies and the loss of previous successful strategies are in constant exchange. Over time, as an acceptance of pain develops alongside a trust in personal intuition, a new structure slowly emerges, forming the last master-theme, a new normal. The structure appears darker as pain continues to be experienced: but it is now seen more as a continued presence than an infiltrator. The rope appears more fragile and less stable than before because of the continued uncertainty caused by unpredictable and variable pain. However, some participants revealed positive experiences represented in the appearance of some brighter cords.