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ORIGINAL ARTICLE

Picturing oneself over time: a multi-modal interpretative phenomenological analysis of pain management trajectories

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Abstract

Background: Chronic pain (CP) can be a disabling condition with impacts that affect the sense of identity of those who live with it. This article idiographically describes the longitudinal evolution of the sense of self of participants following their referral to a pain management service and participation in a pain management programme (PMP).

Methods: Participants were interviewed three times: before they attended a PMP, and 1 and 6 months after the PMP. Data included the drawings of themselves that participants created at each interview and the transcripts of the interviews guided by the drawings, analysed longitudinally using interpretative phenomenological analysis.

Results: This paper describes in detail the cases of four participants: two who experienced a positive albeit troubled trajectory following their PMP and two who did not experience any positive change. The results provide a nuanced account of how the impacts of CP on identity can evolve, with different people engaging with different aspects of a PMP and some people not engaging at all, and how pain self-management strategies enable those that do engage to cope in times of difficulty.

Conclusions: Participant responses to PMP participation are idiosyncratic and interviews with drawings of self analysed longitudinally can help illustrate processes of change.

Significance: Not enough is understood about why some people get limited benefits from pain services. This idiographic longitudinal study illustrates how the impact of CP on identity can evolve when people are introduced to pain self-management, with some embracing change and others resisting it. For clinicians, this study describes four detailed CP individual paths, showing the interaction between contextual and idiosyncratic aspects. This is also the first study to use multiple drawings of self to explore the impacts of illness on identity longitudinally. In a person-centred approach to treatment, the drawings of self could also be adopted as a tool in clinician-patient conversations to gain a deeper understanding of the impacts of living with CP.

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1 | INTRODUCTION

Chronic pain (CP), defined as pain lasting over 3 months not necessarily requiring the presence of a progressive disease or structural abnormality (Turk & Swanson, 2012), is a major health issue in most Western countries. For instance, in the United Kingdom between 10.4% and 14.3% of adults have severely disabling pain, while in the United States prevalence has been estimated at 8%, with women and older adults more affected in both countries (Dahlhamer et al., 2018; Fayaz et al., 2016).

Having CP can be an intimately and profoundly altering experience: people resist their illness because they feel it changes who they are (Toye et al., 2017). The English national health service offers pain management programmes (PMPs), multidisciplinary interventions to help people adapt to life with pain. Qualitative literature has highlighted a strong impact of CP on identity (Toye et al., 2017), yet this aspect is rarely or only partially evaluated as a PMP outcome or targeted by interventions. Identity is a complex construct and some quantitative models have incorporated facets of it. For example, the psychological flexibility model (Hayes et al., 2006) includes a 'self-as-context' component, defined as the ability to distance oneself from one's emotions, thoughts and feelings. In acceptance and commitment therapy (ACT) PMPs, self-as-context, measured using the self-experiences questionnaire (Yu et al., 2016), has been associated with changes in functioning (Yu et al., 2017). However, the question of whether and how PMP attendance might affect one's sense of self more widely in relation to CP remains open.

There is a growing corpus of qualitative studies that have used participant drawings to help convey difficult health experiences more fully (Broadbent et al., 2019). Drawings offer a more direct access to emotions (Kearney & Hyle, 2004); like metaphors, they can facilitate the expression of difficult feelings (Shinebourne & Smith, 2011); they also enable both reflexive and pre-reflexive insight, eliciting additional meaning making during interviews (Boden et al., 2018). Studies using drawings of CP have revealed complex imagery, with pain depicted as an attacker (Phillips et al., 2015) or an object of torture (Kirkham et al., 2015), thus adding depth to narrative descriptions. Drawings of self have been less commonly used in research, so evidence of their value is limited. Cross et al. (2006) asked people with spinal cord injury to draw themselves, observing that the drawings afforded insight into the liminal space between the self and the world. Boden et al. (2018) used drawings of self to explore the relational lifeworld of participants. Since drawings have the potential to disrupt rehearsed narratives (Reavey, 2020), drawings of self may elicit the expression of alternative narratives about self, identity and personal world.

CP is by definition a subjective and emotional experience (Raja et al., 2020), so a qualitative approach, with roots in phenomenology and idiography, such as interpretative phenomenological analysis (IPA), is suitable to investigate its idiosyncratic aspects (Smith & Osborn, 2015). By using IPA in a longitudinal design, with data gathered at multiple timepoints around PMP participation, change (or lack of change) can be captured and analysed (Farr & Nizza, 2019). A few studies have used longitudinal IPA to investigate changing CP experiences: King et al. (2016) explored pain conceptualizations before and after an education intervention; Snelgrove et al. (2013) looked at how the experience of CP evolved over 2 years for participants receiving pharmacological treatment. Both studies present before-after comparisons that, by providing an account of the time before and after the intervention and treatment, illustrate temporal processes of change and/or continuity. The value of using IPA in a longitudinal design lies in the possibility of understanding how experience evolves dynamically, subjectively and in context over time, to form an individual trajectory, which can be further enriched by a participant's prospective and retrospective sensemaking (Farr & Nizza, 2019) and be compared to the trajectory of others to describe alternative temporal flows in experience and cautiously explore causal connections (Neale, 2021).

In this study, to understand what happened after a PMP, longitudinal IPA was used with data gathered at three time points. Data included drawings of pain, self and interviews revolving around the drawings to explore in-depth the experience of CP and its impacts on the sense of identity of participants. Each participant's evolution during the study was reported as one of three types of trajectories: (1) upward and positive; (2) positive but complicated; and (3) negative and unchanging. This article presents the detailed findings from trajectories (2) and (3), with a specific focus on the self drawings to illustrate how the lifeworld and sense of identity of participants evolved: some had a positive change albeit with some personal drawbacks, while others experienced little or no change. A detailed report of pain and self drawings from trajectory (1) has been published separately (Nizza et al., 2022).

2 | MATERIALS AND METHODS

2.1 | Participants

Participants were women, aged 40–60 years, unemployed and with CP for more than 2 years, who had been referred to a National Health Service Community Chronic Pain Service (CCPS) in South-East England. Participants discussed in this article had the following characteristics:

Positive but complicated trajectory:

1. Gillian, aged 46, diagnosed with fibromyalgia, 4 years with CP, taking anticonvulsant medication and receiving tai-chi, counselling and hydrotherapy from the service.
2. Lauren, aged 51, diagnosed with osteoarthritis and lumbosacral radiculopathy, over 17 years with CP, taking opioid painkillers and receiving tai-chi and physiotherapy from the service.

Negative and unchanging trajectory:

1. Helen, aged 60, diagnosed with fibromyalgia, over 25 years with CP, taking opioid painkillers, anticonvulsant medication, antidepressants, sleeping pills and receiving counselling from the service.
2. Alison, aged 51, diagnosed with lower-back pain and ME, 5 years with CP, taking antidepressants and receiving a TENS machine from the service.

Note that all participants took part in the PMP and then each was offered different types of support by the CCPS, depending on their clinical needs. The PMP was non-residential and group-based, comprising four 4-h weekly sessions. It combined elements of education, CBT and ACT, including relaxation and mindfulness sessions, but no session explicitly addressing issues of identity.

2.2 | Recruitment and data collection

Ethical approval for the study was granted by the NHS London-Stanmore Research Ethics Committee in 2015 (15/LO1872).

The study was presented during an introductory session to the CCPS. Those interested were handed a study information sheet and contacted a few days later to confirm participation, ask questions and arrange the first interview. A few months later, at their nurse's discretion, participants were referred to the PMP. One month after completing the PMP, participants were interviewed a second time, and then a third time 5 months later. Interviews took place in surgeries, lasting on average 78 min.

At the first interview, after reassurance that the artistic quality of drawings was unimportant, participants signed a consent form. They were then left on their own for 15 min to create a drawing of their pain on an A4 blank sheet of heavy paper with coloured pencils, crayons and felt-tips. They were asked: '*draw a picture of what your pain feels like to you*'. Then the researcher returned and, leaving them alone for another 15 min, asked: '*draw a picture of yourself as you are now*'. Then the semi-structured interview started, focussing on one drawing at a time and asking participants to describe

each drawing, why it was drawn that way and their thoughts looking at it. The second and third interviews had comparable questions, except that, in the second half, drawings from previous interviews were reviewed to stimulate reflection.

If a participant became tearful during the interview, they were given time to recover and the option of stopping the interview. The interview was followed by a debrief and no one requested further support. Interviews were audio-recorded and transcribed verbatim. IEN, the interviewer, kept a reflexive journal and was supervised clinically by JAK, a senior counselling psychologist expert in CP.

2.3 | Analysis

Participants were assigned pseudonyms and, if necessary, drawings were anonymized through electronic editing. For each participant, there were three pain drawings, three self drawings and three interview transcripts for analysis. Data were analysed inductively, idiographically and longitudinally, before comparing cross-case.

For each interview, first the pain and self drawings were analysed using a visual analysis framework (Boden & Eatough, 2013): the image was considered both as a gestalt and analysed systematically, by detailing its different aspects (composition, balance, geometry, materials, texture, colour, depth/perspective, etc.) in a descriptive narrative. The purpose here was for the researcher to gain an in-depth understanding of each image before engaging with the participant's interpretation of it. Next, notes and experiential statements were added to the transcript, as per the IPA method, then collated into personal experiential themes and linked to the relevant elements of the drawings (Smith et al., 2022). There was also a focus on prospective views (participants' considerations on newly created drawings), and retrospective views (reflections on change, particularly through drawing comparison). The output of this phase of the analysis was a table of personal experiential themes for the time point, which revolved around the drawings and included quotes from the transcripts.

For the idiographic longitudinal analysis, first the drawings were compared with each other to identify similarities and differences. Again, this process was guided by a visual analysis framework (Boden & Eatough, 2013) and documented in a narrative. Then the tables of personal experiential themes from interviews 1, 2 and 3 and the drawings were considered together to identify specific aspects of the narrative and/or drawings that seemed to recur over time, either evolving or remaining the same. These aspects were described as trajectories, with a focus on what seemed to have occurred between timepoints and documented using

participant quotes from each timepoint. Each participant's experience was then summarized into an overall 'from-to' trajectory that encompassed the essence of their evolving narrative and drawings.

Finally, individual trajectories were compared across-case to develop three trajectory types: (1) upward and positive, (2) positive but complicated and (3) negative and unchanging. As is common in IPA, the analytical stages described above were highly iterative. The drawings had a central role in the analytical process for their ability to

capture the complexity of participants' experience and, when described, enable participants to give voice to aspects of their experience that would normally be difficult to express.

In the next section of this article, the self drawings of four cases are presented: two from the (2) positive but complicated trajectory group and two from the (3) negative and unchanging trajectory group. Drawings from all participants are also presented in a single table (Figure 1), with one row per person, and a column for



FIGURE 1 Self drawings at Time 1 (T1), Time 2 (T2) and Time 3 (T3) for Gillian and Lauren and for Helen and Alison.

each timepoint, to enable horizontal comparisons between the three drawings of a person and vertical comparisons between the drawings of different participants at the same timepoint.

3 | RESULTS

The positive but complicated trajectory group includes Gillian and Lauren, who experienced a change for the better over the course of the study, albeit with some difficulties; the negative or unchanging trajectory group includes Helen and Alison who seemed to remain psychologically static, but for different reasons. The drawings provide a nuanced account of these trajectories.

3.1 | Positive but complicated trajectory: Gillian and Lauren

3.1.1 | Gillian: From losing herself to being in control

Gillian worked hard to regain control over her life and, to a certain extent, she succeeded. Initially, she had been distressed for having lost her previous identity. Through the techniques she learnt from the CCPS she re-engaged with daily life. A crisis then challenged her balance and became the opportunity for Gillian to express an agency and a control that felt new.

Gillian's first drawing (Figure 1, Gillian T1) contains multiple versions of her: reading, with 'candyfloss brain', crying and sleeping. There are also two ugly masks: a red one representing rage and a green one representing envy. Gillian had previously had an active lifestyle and now her life was limited to the few activities depicted in her drawing. This change was distressing and affecting her sense of identity:

I've always been an active outdoors person and my life has changed completely, I am not me anymore, I am just a completely different person and I want to go back [...] [I] just want to... [pauses] be me again and not this shell of what I am or what I used to be [Gillian, T1]

The lack of activity forced upon Gillian by the pain had transformed her life and, by extension, her sense of identity. The blankness and desolation in the sad and absent expressions of the top three figures illustrate her sense of being 'a shell' of what she used to be, as if her core had been lost to the pain. Gillian wanted to 'go back', because she felt no acceptance of her new life, nor any identification with the new person she had become. This sense of alienation was

accompanied by negative emotions, symbolized by the red and green masks in her drawing.

Gillian's lively second drawing created after attending the PMP is permeated with colour and positivity (Figure 1, Gillian T2). It shows a smiling figure standing under a blue sky with the sun shining bright. Around the figure there are positive scenes: tea with friends, walking dogs, picking flowers and working at a computer. Some scenes were already reality for Gillian, others were more of an aspiration, but the general tone was of hope for the future ('*I am starting to see a light at the end of the tunnel!*'). These optimistic words and the sunny drawing were in contrast with the bleak picture of multiple unhappy selves drawn only a few months earlier. Thanks to a rigorous pacing regime, Gillian's pain symptoms had improved, and she had resumed some social life (having tea with friends bubble). This made her hopeful about returning to other activities, such as work. However, Gillian was also realistic, for instance, about the impossibility of practicing sport again:

I don't think I'll ever be able to do that [sport] and that's fine. I've sort of, that was the past me, which before [...] I would have been desperately upset about and wanting to get back to [...] now I know I am never going to be able to do that again [Gillian, T2]

There is a sense of acceptance in this extract ('*now I know I am never going to...*') in contrast with Gillian's previous refusal to accept what was occurring in her life. Here she talked of a 'past me', who would have wanted to 'get back to' her old life, almost quoting the words from her first interview ('*I want to go back*'). Things had changed: Gillian knew that she could no longer be her old self, instead, she was expressing a new calm and realistic self.

At her third interview, Gillian was having a flare up. Her drawing (Figure 1, Gillian T3) describes her response to the problem that had triggered the flare-up. The drawing contains different versions of her: crying, lying in bed with worrying thoughts, screaming and having tea with friends. Her tone was distraught:

I don't know how to fix this situation [...] I've tried absolutely everything and nothing I do works [Gillian, T3]

Although the situation was serious and Gillian was upset, reading between the lines of her quote, a sense of agency transpires. For instance, when saying '*I don't know how to fix this situation*' and '*nothing I do works*', she was looking for actions that she could undertake to improve the situation. Later in the interview, her sense of agency became even more explicit:

you can't be stress-free completely, but you can do things to help yourself as much as possible and I just need to do whatever I can, I think, to help myself [Gillian, T3]

Despite feeling at a loss on how to resolve the problem, Gillian was taking responsibility for her wellbeing. In fact, the inclusion of tea with friends among the scenes of her drawing illustrates a coping mechanism. Gillian was expressing agency and actively coping.

3.1.2 | Lauren: From raging to being real

Lauren's trajectory was complex: initially she was angry with herself; the PMP brought a breakthrough where she became more focused on her own needs and prepared to face previously ignored health problems.

Lauren's first drawing (Figure 1, Lauren T1) contains two versions of her: on the left, she is standing in crutches before three pleading children. She appears unstable and sad, with a black downward grimace, a broken heart and fumes radiating from her head. On the right, she is on a wheelchair, holding two smiling children in her lap. Her heart is whole, she is smiling, with musical notes in the air. Lauren said that on crutches she was sad and angry because she was 'wobbly' and unable to pick up her grandchildren. In the other figure she was happy because, despite the wheelchair, she could cuddle the children. Although the drawing might suggest that the wheelchair was her preferred option, she seldom used it because it evoked complex feelings:

instead of being like that [crutches], I make myself be that [chair], why struggle when there's no need? I've been given this stuff to use for quality of life, so damn well use it, stop being so stubborn. But as much as I am saying that to you, at the same time, when it actually comes to using it, I hate it, I absolutely hate it. It's a godsend because I have had some really great days out with the family [...] but I do feel like I'm slowing them all down [Lauren, T1]

Lauren did not like using the wheelchair because it made her feel like a burden to others. She encouraged herself to use it, but with harsh words ('*make myself*', '*damn well*' and '*so stubborn*'). These aggressive and self-deprecating expressions reveal an inner conflict and negative emotional state: Lauren hated herself for not being what she thought she should be and the fumes from the first figure's head illustrate this rage. At the same time, she was exhorting

herself to see the positive ('*it's a godsend*'). The inclusion of two versions of herself in the drawing reflected her struggle: the first figure represented her frustration and sadness and the second figure, with its red smile, was an injunction towards a more positive outlook.

Lauren's first interview was distressing and tearful. Her drawing shows her embroiled in a narrative of self-hatred, not accepting her disability and feeling guilty towards her family.

Lauren's second drawing (Figure 1, Lauren T2) is a window with open shutters radiating light and labelled as '*ME—opened doors to all possibilities*'. Above the window are a large heart, a big smile and a bright sun; below there are her grandchildren. The drawing feels expansive and joyful. This is Lauren's description:

Before I was kind of not coping with anything, trying to be positive, but not quite coping [...] this is me breaking the doors open and saying, basically, without being rude, bugger the negativity! Let's just do what we can do, day-to-day [Lauren, T2]

Lauren's drawing was an emphatic affirmation of her determination to cope by being open to the future and pragmatically living day-by-day.

Bonding with other PMP participants had allowed Lauren to see herself differently: '*we didn't look at each other as a problem or a disability*'. Her previous perception of herself as disabled and her self-hatred had dissolved through contact with other people who were in a comparable condition. The radiating window and the '*positivity*' label in her drawing illustrated this new expansive outlook.

In Lauren's third drawing (Figure 1, Lauren T3), she appears as a full figure covered in pain marks and with a detached head floating just above her body. There are tears on her face and cartoons to word her thoughts. Lauren's mood at the start of the interview was low:

I feel like I've gone three paces back, I just feel like I was in a really good place the last time I saw you and suddenly it's all gone out of the window, I just feel like I need a break. [Lauren, T3]

In the picture, '*three paces back*', appearing as '*1 → 2 → 3*' below her, illustrates Lauren feeling dejected for a new illness diagnosis that would require surgery. However, unlike before, she now had the ability to cope. Talking about her detached head in the drawing, Lauren explained that, using a kind of self-hypnosis, she could abstract herself from her body and find respite.

After looking at her current drawing in the context of her previous ones, Lauren's tone changed and how she described her current state became more positive.

when you put this whole lot together [drawings], I haven't been thrown back, I haven't gone back those three footsteps, I just felt like that, it's just another thing to deal with and I will. So, yes, I've coped with the major pain, I can cope with that [Lauren, T3]

Learning to manage her CP had given Lauren the confidence to cope with her new health problem.

Comparing Lauren's three drawings it's interesting to observe that the main subject of her third drawing is her, with her pain and coping strategies, while her family only appear in one of the bubbles with many occurrences of 'PAIN'. Family was on her mind, possibly as a preoccupation, but had less space than in earlier drawings. Lauren was representing herself as a full figure, over the whole page, putting herself at the centre of her narrative. Lauren's initial self-loathing had been linked to feeling guilty for failing her duties as a grandmother. Over time, as she learnt to accept her condition and its limitations, she found the strength to focus on her own needs. The PMP had been pivotal in this process, because she had felt supported and encouraged to live happily within her limits. Her last drawing was of her 'real' self with pain, tears and a clear mind, psychologically stronger and determined to live her life to the full.

3.2 | Negative or unchanging trajectory: Helen and Alison

3.2.1 | Helen: Increasingly isolated and unable to act

Despite enjoying the PMP and receiving individual counselling, Helen's drawings of herself changed for the worse, as she became more isolated and unable to help herself.

Helen's first drawing is dense and occupies only half the page (Figure 1, Helen T1). She appears as a full figure, surrounded by lightning marks, question marks and symbols of her current life: a walking stick, a toilet with a falling ring, two chairs and a scooter. The fullness and position of the drawing are intentional:

That's how I feel about my future, that I haven't really got one [...] I can't think of

tomorrow, I can only do one day, because this is enough to cope with [Helen, T1]

One half page was the present, full of the things that Helen was having to 'cope' with, while the other half was empty because she was unable to see a future for herself.

As indicated by the text in her drawing ('drugs', 'clinics', 'assessments', 'Dr's'), Helen's concerns were mostly health-related, while the scooter symbolized how her adult sons were oblivious to Helen's needs:

"Oh, do you want to use your scooter?" I wanna go, well sometimes I do though, "Yeah, it's a fashion accessory, you know!" [Helen, T1]

Helen was irritated by her sons' lack of understanding that a scooter is not a choice, but a necessity. Helen's had been a tragic life of ill-health and traumatic experiences and her first drawing showed her low, isolated and dissatisfied with the people around her.

In her second drawing (Figure 1, Helen T2), Helen's face appears behind bars, again surrounded by zig-zag signs and question marks. Her expression is scared and unhappy, with tears rolling from large sad eyes, looking straight at the viewer, with a single-tree island outside the cage. Helen said:

there are days where I just want to cry, it's like this, this desert island, this is where I live [...] and these are bars, it's really about the isolation, [...] it is how I feel lots of days, but I never, rarely or never really show that to the world [Helen, T2]

Helen continued to feel isolated, particularly from her family ('the world'). She was also overwhelmed by sad emotions, expressed in her drawing, but not in 'real life'. The ongoing lack of family support contributed to Helen chastising her emotions. She again discussed her mobility scooter, explaining that her sons' attitude made her feel bad about herself ('it makes me feel that I am a nuisance to need it'). Although her sons triggered resentment for their lack of understanding, they also triggered a sense of guilt:

I was brought up to have a massive guilt complex [...] I don't think my boys can really accept anything wrong with me [...] mums are meant to be strong aren't they? [Helen, T2]

Helen was embroiled in an ambiguous relationship with her sons: she felt guilty but also blamed them for not responding to her fragilities. When saying *'mums are meant to be strong, aren't they?'* it was unclear whether she felt she should be strong, or whether she was lamenting their immaturity expecting her to always be strong.

As the study progressed, it became obvious that for Helen change was difficult. Helen had enjoyed the PMP and understood that she needed to help herself. Talking about her second drawing, she said:

If I can just get out of here [cage], but that's down to me really, that's what the swimming I could be doing and the fibromyalgia [support group] and then tai-chi. So that's three things that I could be doing, that could help me. We are our own worst enemies, aren't we? [Helen, T2]

Helen had been offered support activities from the CCPS but had not engaged with any. The cage in her drawing was self-made, it represented her self-sabotaging attitude, which stopped her from helping herself: she was her *'own worst enemy'*.

In her third drawing, Helen is again behind bars, but with a full figure (Figure 1, Helen T3). Her body is mutilated in various points. Again, the sense of isolation is central:

I knew that I had to draw myself in a cage or in a prison, if you like, because that's how I feel at the moment [Helen, T3]

Helen felt enclosed, unable to move away, partly because of the bars and partly because she appeared to have no hands nor feet (*'I've lost my feet and my hands'*) and a body *'broken'* by pain. The feeling of isolation was persisting. Her face in her third and second drawings was strikingly similar: with wide teary eyes and a frowning mouth. While in the second drawing the bars had been almost invisible, this cage was well-defined, relatively small and trapping her like an animal.

Reviewing the drawings together, Helen realized the full extent of her unhappiness. She knew she needed to change, but felt an inhibiting force:

I need to change me, this is silly [tapping the drawings] and it is a waste of time. Two weeks ago that lady said to me, "Why don't you make an appointment to see [nurse]?" "Yeah, I'll think about it." Then another two weeks. I could have done it, though, couldn't I? [...] [husband] always says, if I am in a shop

and I see something [...] if it was for [...] anyone else, I would just buy it, if it's for me, I am going to have a big conversation with myself and [...] I think a lot of mums are like that [...] it all boils down to our self-worth, doesn't it? [Helen, T3]

Helen recognized a pattern of procrastination when doing things for herself and ascribed it to her motherly instinct and lack of self-esteem. These were deeply rooted causes for inaction and a lot of motivation would be needed for her to break free. Family dynamics made looking after herself a low priority. The trajectory of Helen's drawings is negative, with her appearing increasingly sad and isolated. Her narrative reveals an awareness of her inability, despite the support available, to act and help herself.

3.2.2 | Alison: An ongoing low mood and lack of engagement

Alison's drawings were basic and not very expressive, accompanied by a narrative of resentment. She did not engage with the CCPS and maintained a relatively unchanged low mood.

Alison's first drawing (Figure 1, Alison T1) is simple and entirely monochromatic. It is a stylized frowning face surrounded by speech bubbles with negative emotions (*'depressed'*, *'angry'*, *'sad'*, *'useless'* and *'lonely'*). She described them forming a vicious circle:

this is the circle and you have to break it, but how do you break it? Because you can try and break it, you can take antidepressants which help you come out of depression, but, you always feel lonely and this, you always feel useless, because there is always something that you used to be able to do that you can't do, and it's just like another thing off the tick-list, "Oh, there's another thing I can't do," instead of concentrating on the things that you can't do, like they say, concentrate on the positives, what you can do, but when you're having them 'can dos' chipped away to 'you cannot do' it's hard [Alison, T1]

Alison's negative emotions were connected because they could trigger each other and whenever she was able to control one, another would crop up. At the root of these emotions were the things she felt no longer able to do because of CP. She appeared to be keeping a mental *'tick-list'* of activities

(*'can dos'*) and whenever she discovered something she could no longer do, the activity would come off the list, reactivating the cycle of negative emotions. Losing her preferred activities made her feel *'useless'* and *'lonely'*. Anti-depressants were a partial solution: they could lift her mood, but not stop her life being *'chipped away'*, one activity at a time.

Alison had lived with depression for a long time. She had received counselling and various forms of therapy prior to her CCPS referral. She had been on antidepressants for years and said that she had already tried the techniques and types of support that the CCPS could offer (e.g. tai-chi, mindfulness). From the start, she displayed a pre-emptive attitude, evident in the quote above when she rebuts the common advice to *'concentrate on the positives'*. Although she claimed to *'be willing to try anything'*, she discarded what was suggested and her feelings towards the service appeared hostile:

I went to the pain clinic, she gave me a TENS machine, asked me a load of questions, gave me a TENS machine, and I've not seen her since [Alison, T1]

The tone in this quote was resentful: even the prescription of a TENS machine, which had helped relieve her pain, was described in aggressive terms (*'I've not seen her since'*). Alison's first drawing well-illustrated her low mood and her frustration for what was happening to her. Her anger extended to the CCPS, yet she was determined to attend the PMP hoping to learn something new.

Alison's second drawing was a fairly neutral figure holding a walking stick, with her short hair, straight mouth and blue eyes (Figure 1, Alison T2). She said little about the figure itself, except that the stick was an important part of her life:

it's my saviour at the moment [...] I feel more secure when I've got it, it's like a comfort blanket [Alison, T2]

Alison's stick made her feel safe. She appreciated the value of aids (*'aids are a good thing and I'll embrace them now, I don't want to, but I'll have to'*), since they had been discussed at the PMP (*'now'*), but she did not acknowledge a source for her change of attitude. PMP participation had not been enjoyable for Alison. She had *'hated every single minute of it'*, she felt it had not taught her anything that she did not already know, and had felt awkward during the *'meditating malarkey'* at the end of each session. She appreciated only the session on spine anatomy, where she had been able to *'actually see what was wrong'* with her.

Alison's third drawing (Figure 1, Alison T3) is strikingly similar in subject and layout to her first one: a

monochromatic round face, surrounded by bubbles with descriptors of her low mood: *'can't be bothered'*, *'want to be on my own'*, *'fed up'*, *'sad'* and *'tired'*. At the side, there is also a thermometer to indicate that she had *'no energy'*. In the past, Alison had described some of the emotions she listed (*'sad'*, *'fed-up'*, etc.), but she was expressing *'cannot be bothered'* for the first time:

I am tired and I'm fed up, but it's like I've got no feeling, I don't know if I am explaining it right, it's like numb, and I don't like feeling like this, because it feels like it drags me down and it makes me worse [Alison, T3]

Alison was feeling *'numb'*, and at the start of her third interview her tone of voice was low and her answers restrained, suggesting worsening depressive symptoms. The tone changed after Alison reviewed her self drawings all together, which allowed her to temporarily see herself from outside:

even if I didn't know who I was and I looked at these, I would be quite worried [...] because it looks like a very sad depressed person, who's got a lot of issues [Alison, T3]

This realization had a lifting effect on Alison's mood: she became more talkative and started to express more anger, particularly towards HCPs. She complained about not receiving enough support with a new medication that made her feel numb and, again, was negative about the PMP and the staff:

It's no good medical staff standing up there telling you to do this, do that, do this, do that when they've never been through it, because it's all right saying, yes, you can do it, you can do it, if I could do it, I would bloody do it, I don't need somebody telling me to do it! [Alison, T3]

Alison also felt that, on account of not having ever experienced CP, HCPs had no authority to tell people what they should do and was using this rationale to dismiss the contents of the PMP. At a deeper level, she seemed to be justifying her lack of change over the course of the study. In the quote above she said that she wasn't doing what had been suggested because she was unable to; elsewhere she explained that having suffered with CP for nearly 6 years, she had already done everything that could be done (*'I think I have changed everything I can change, I can't change any more'*). She had consistently refused to engage with any of the proposed self-management activities, particularly pacing. In this last interview, Alison appeared more defensive than she had ever been. Her drawings showed no change,

and she was justifying her refusal to engage, as if to avoid being blamed for her lack of improvement and for still being unwell. She felt that the CCPS had '*not changed any part*' of her life '*whatsoever*': which she seemed to perceive as a failing on the part of the service, not the consequence of her refusal to follow advice.

4 | DISCUSSION

The study objective was to understand what can happen after CCPS referral and PMP attendance. Three trajectories were identified, with one group showing a notable change (Nizza et al., 2022), one having a complicated but still positive outcome and a third group experiencing no change. This article presents the experience of the latter two groups through drawings of self.

Initially, Gillian drew multiple versions of herself and felt unable to reconcile with the inactive, confused, jealous and angry person she had become. Lauren drew herself with crutches and wheelchair, fighting the identity they symbolized and hating herself for failing her family duties. Their experience echoes evidence that people with CP fight to retain their old identity and struggle to adjust to who they have become (Hellstrom, 2001; Smith & Osborn, 2007; Toye et al., 2013). In contrast, Alison was locked in a vicious cycle of low mood, while Helen appeared hopeless in a jumble of medical and family references. Both had a history of depression, a common comorbidity in CP sufferers (Lerman et al., 2015).

Shortly after the PMP, Gillian and Lauren appeared better, but their positive trajectory was disrupted at the third interview when Gillian had a flare-up and Lauren faced new physical problems. The setback was a shock, but it was also an integral part of their journey towards learning to manage their CP. Flare-ups and other disruptions are common in CP and the purpose of self-management techniques, particularly pacing and mindfulness, is to enable containing such events (Nielson et al., 2013).

Gillian and Lauren's evolution can also be understood as growing acceptance, a construct widely associated with CP (Hayes et al., 2006). Initially Gillian had expressed anger for the life changes caused by pain. After the PMP, she was serene in recognizing that resuming her previous lifestyle was no longer an option. She had come to accept both her pain and its impacts on her life. Lauren expressed her acceptance by being more '*open*' about the effects of pain in her life. General acceptance of pain and its impacts is a significant predictor for the physical and psychological aspects of functioning (Trainor et al., 2019).

For the second group, the PMP was not a successful experience: Helen was a passive observer, while Alison did not engage and was dismissive of pain management

strategies. As the study progressed, Helen continued to feel cut off from the world and, despite recognizing that the bars on the cage of her drawings were self-made, was unable to help herself. Alison seemed locked in a state of resentment.

The review of pain self-management intervention outcomes by Devan et al. (2018) can help to understand Helen and Alison's experience. Some PMP participants are fixed on a biomedical explanation for CP, which prevents acceptance and undermines the motivation needed for self-management. Ongoing psychological distress also negatively influences the ability to self-manage, because fear/avoidance mechanisms lead sufferers to dismiss strategies such as pacing, and depressive symptoms affect problem solving abilities and lead to self-blame. An unsupportive environment (conflict with clinicians and lack of acknowledgement by significant others) can also be a barrier to self-management.

The psychological flexibility model (Hayes et al., 2006) is the most useful to understand how different trajectories can develop after PMP participation. Psychological flexibility manifests through various constructs (including acceptance and self-as context) and can be summarized as the openness to challenge one's sense of oneself and one's behaviour patterns, as Gillian and Lauren seemed able to do. In contrast, Alison's and Helen's stagnation could be ascribed to psychological inflexibility: they were unable or unwilling to challenge their own psychological status quo.

Beyond models, what is special in this study is the illustration of how the different biopsychosocial factors combine and concur to create a person's CP situation and how the CP intervention stimuli interact with the specifics of the person's life to bring about a change or for a change not to happen. The drawings contribute to make this account more vivid, for the depth and reflection they enable in participants, and for their ability to resonate with the viewer.

Some self representations in this study were literal, like Gillian's multiple selves doing things; others contained metaphors, ranging from simple ones (e.g. the sun to indicate serenity or a grimace to show unhappiness), to more elaborate ones, such as Lauren's new-found openness represented with an open window or Helen crying in a cage to convey her feelings of isolation and despair. These metaphors served to communicate complex experiences and emotions in a concise and impactful manner, often offering a '*safe bridge*' for emotions that were difficult to acknowledge (Shinebourne & Smith, 2010). Some metaphors communicated directly with the viewer (e.g. Helen's caged Self), while some, such as Lauren's detached head, relied on the participant's narrative for interpretation.

Self drawings have been used in studies investigating various health conditions (Broadbent et al., 2019),

but, to our knowledge, never to research CP. Being explicitly asked to make a drawing of yourself gives a specific focus to the act of drawing because it forces you to think about yourself, your situation and how others see you. In this study, drawings of self raised issues of identity, sociality, embodiment, temporality, mood and project (Ashworth, 2016).

Applied longitudinally, self drawings illustrate the unfolding of events and also uncover 'how the narrative of a life—the life as told, interpreted and understood—is continually re-adjusted to the life as lived and experienced' (Neale, 2021, p. 178). The moment in the final interviews with Helen and Alison where all the drawings were reviewed together felt like a moment of reckoning for both women. The dismay they both expressed raises the ethical issue of how, as researchers, we can protect and support participants when the research process elicits difficult emotions that remain unresolved in the research setting. In line with research ethical guidelines and our protocol, we relied on the safety net provided by the CCPS. In fact, Helen was still having counselling sessions with the CCPS psychologist, whereas Alison was reminded that she could seek appropriate support there.

CCPSs aim to help people with CP manage their condition by reviewing their medication, educating them on CP and its impacts, teaching them self-management techniques such as mindfulness and pacing, and offering opportunities to share experiences with fellow sufferers. This study illustrates how CP self-management is not for everyone and does not work in the same way for all those that engage with it. The results are a nuanced account of the dynamic interaction between the input that each participant received from the service and their responses, actions and sense making around the process; we see the impact of time and how change can unfold involving different aspects of participants' lifeworld or not happen at all. The choice of recruiting participants from a CCPS inherently limits the portability of findings to a different type of service or context.

Many life occurrences can have an existential impact that phenomenological research should aim to uncover (Smith, 2019). Answering direct questions related to self can be difficult and understanding about self often emerges from interviews only indirectly and in a fragmented manner, when participants discuss their life-world idiosyncrasies. In this study, drawings of self facilitated in-depth conversations and reflections on existential topics. The longitudinal design then enhanced this potential. Discussing matters of existential import is paramount in health research where the focus is often limited to the symptoms of a condition and its practicalities. Understanding the existential impact of an illness enables clinicians to address such impacts with potentially profound consequences on the quality of life of affected

individuals. This is particularly the case with CP whose effects on identity have proven, both in this study and elsewhere, to be an obstacle to adapting to the new life CP brings. This study also illustrated how drawings of self can elicit a deep sense making around illness and, occasionally, hot cognition, giving insight into the dynamic thought processes that characterize being ill (Smith, 2019). Thus, the recognized value of illness drawings (Broadbent et al., 2019) is extended and potentiated by drawings of self. Methodologically, IPA could be used with illness and self drawings to investigate the existential aspects of other chronic conditions, particularly those which are known to have a life changing physical or psychological impact. Self drawings with IPA could also be used for other non-health-related research topics where issues of identity are particularly relevant, such as major life transitions.

AUTHOR CONTRIBUTIONS

I. E. Nizza made a substantial contribution to the conception and design of the work, acquisition, analysis and interpretation of data, drafting the work and approving the final version to be published. J. A. Smith made a substantial contribution to the conception and design of the work, analysis and interpretation of data, revising it critically and approving the final version to be published. J. A. Kirkham made a substantial contribution to the conception and design of the work, to the acquisition of data, revising it critically and approving the final version to be published.

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CONFLICT OF INTEREST STATEMENT

The authors report there are no conflicts of interest to disclose.

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