

# **Put the illness in a box: a longitudinal interpretative phenomenological analysis of changes in a sufferer's pictorial representations of pain following participation in a pain management programme**

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## **Abstract**

Combining participant drawings with interviews can stimulate deep reflection and allow the inexpressible to be expressed. This case study uses visual methods to illustrate the nine-month self-management journey of a female chronic pain sufferer. The participant drew a picture of her pain at each of three interviews and the drawings were used to discuss the changing impact pain was having on her life. Drawings and transcripts were jointly analysed longitudinally using Interpretative Phenomenological Analysis, revealing how, as control is regained, a sufferer's relationship with their chronic pain can visibly change and how the drawings, when reviewed retrospectively, enable insight and ownership of progress.

## **Introduction**

In Europe, between 25-35% of adults report experiencing chronic pain, a physically and psychologically debilitating condition, difficult to control pharmacologically and often associated with depression and anxiety.<sup>1, 2</sup> Chronic pain is subjective, dynamic and multidimensional, affecting most aspects of the lives of sufferers. Quantitative paradigms have generated scales and models of pain, while qualitative studies have provided the deepest understanding of the complexities of living with it. In 2015, the British Journal of Pain published a special edition to explore the contribution that qualitative research makes to the understanding of pain.<sup>3, 4</sup> Patients have reported not being able to make sense of their pain and finding social interactions challenging for the stigma attached to pain and the tendency for pain to reveal undesirable aspects of themselves.<sup>5</sup>

In some areas of the United Kingdom, community pain management services offer support for sufferers delivering psychological, behavioural and educational interventions, including Pain Management Programmes (PMP), group interventions

lasting several weeks and developing key self-management skills such as relaxation, mindfulness, goal setting, pacing and sleep hygiene.<sup>6, 7</sup> Evidence suggests that such programmes, most of which are based on Cognitive Behaviour Therapy principles, are associated with marked improvements in quality of life, producing positive changes in disability, psychological distress and, to a lesser extent, pain.<sup>8</sup> However, understanding of the longitudinal psychological trajectory of patients is limited.<sup>9</sup>

Interpretative Phenomenological Analysis (IPA) has provided rich accounts of the existential impact of chronic pain.<sup>10-12</sup> Smith and Osborn argue that IPA's grounding in phenomenology and hermeneutics makes it particularly suitable to explore the complex and emotionally-laden experience of pain, while IPA's idiographic commitment allows the understanding of its idiosyncratic aspects.<sup>13</sup>

The elusive nature of chronic pain has also stimulated the adoption of visual methods, through which the unexplainable experience of pain can be examined and conveyed more fully. Interestingly this can itself be seen connected to a growing interest by qualitative researchers in incorporating visual methods within their designs.<sup>14, 15</sup>

In relation to pain, photographs representing chronic pain co-created by sufferers and an artist can facilitate clinician-patient communication during consultations.<sup>16</sup> Drawings can give insight into the imagery of sufferers: an analysis of artwork produced by participants at the start and the end of a PMP found that the images of recovery revolved around a redefinition of the self.<sup>17</sup> In a questionnaire-based study, pain was

represented as an aggressive attacker.<sup>18</sup> Kirkham et al. combined drawings with interview data by asking seven women to draw images of their pain and directly discuss them in a semi-structured interview.<sup>19</sup> The images were powerful metaphors, depicting pain as a sinister, violent and punitive aggressor and the drawings, expressive in themselves, offered new ways of describing the indescribable. These findings confirm that the use of visual artefacts in interviews enhances reflexivity and can be an integral part of sense-making.<sup>20</sup> Particularly in health research, drawings allow participants to think of their disease differently, possibly because knowledge is expressed through emotions more than cognitions.<sup>21, 22</sup> Drawings, like metaphors, can act as a “safe bridge” towards the expression of painful feelings.<sup>23, 24</sup>

The interpretative nature of the IPA analytical process is described as a “double hermeneutic”, in which the researcher is making sense of the participant’s sense making.<sup>10</sup> When visual methods are used within an IPA study, parallel and multiple hermeneutic circles are created; for example, the participant is offering an account of their picture, the researcher is analysing the visual depiction and the participant’s reading of it. This results in more complex interpretations that can generate particularly rich results.

This article presents a single case from a wider study where IPA interviews with drawings were used longitudinally, to understand how pain and the sense of identity of sufferers changed following participation in a PMP. Participants were 40-60 year olds,

unemployed and suffering from chronic pain for at least 2 years. The depth achieved by focusing on a single case allows for a true idiographic appreciation of the nuances of the stages of a chronic pain sufferer's journey towards recovery. The selected case is comparable to the other participants in the study, most of whom experienced some positivity in their trajectory. Methodologically, it illustrates the opportunity afforded by longitudinal visual data to dynamically explore pre-reflexive, reflexive and retrospective understandings within an interview.

## **Methods**

### **Participant**

Jane is a 47-year old diagnosed with fibromyalgia, degenerated disks and depression, who had been in pain for 3 years. She had been prescribed tramadol and pregabalin and was self-medicating with paracetamol, vitamin B, vitamin D, zinc, calcium and magnesium.

### **Recruitment and data collection**

Ethical approval for the study was granted by the NHS London-Stanmore Research Ethics Committee in 2015.

Jane was recruited shortly after being referred to a National Health Service Community Chronic Pain Service in South-East England. The study was advertised during the Pain

Education Session (PES) that all patients attend when they join the service. A few months after the PES, some patients can be referred to a four-week PMP.

The three interviews were two weeks after attending the PES, four weeks after the PMP and six months after the PMP, and lasted 50", 42" and 45" respectively.

During the first interview, after signing the consent form and having been reassured that the interest was not in the artistic quality of her drawing but in its contents, Jane was left alone for 15 minutes. Using an A4 blank sheet of heavy paper and coloured pencils, crayons and felt-tips, she was asked to "*draw a picture of what your pain feels like to you*". Then the researcher returned and asked her to "*draw a picture of yourself as you are now*", during 15 more minutes.

When drawings were complete, the semi-structured interview commenced, which was audio-recorded and later transcribed verbatim. The interview schedule focused on one drawing at a time: Jane was asked to describe the drawing of her pain, why she drew it as she did and what her reaction was looking at it; then she described the drawing of herself with similar probing questions, and questions on how the pain made her feel about herself, how she thought others saw her and how she would have liked to feel; finally, she was asked about the experience of drawing.

The second and third interviews followed a similar structure initially, but then earlier drawings were also presented to comment on similarities or differences.

Interviews were conducted by the first author, who holds an MSc in Health Psychology. The interviewer kept a reflexive diary and received clinical supervision by the third author, a senior counselling psychologist specialising in chronic pain.

### **Analysis**

The data available for Jane included three drawings of pain, three drawings of self and the transcript from three interviews. This case focuses on the analysis of the pain drawings and the corresponding portions of transcript.

Jane was assigned a pseudonym and the names within her pictures were electronically edited to ensure anonymity.

Data were analysed chronologically, one interview at a time, before proceeding to the longitudinal comparison between time points. Drawings were analysed on their own, using the visual analysis method proposed by Boden and Eatough, inspired by compositional analysis.<sup>14, 25</sup> Then each transcript was analysed inductively searching for themes according to the IPA method, linking the themes to the pictorial elements of the drawings, when possible.<sup>10</sup> The analysed data includes both prospective views (discussion of newly created drawings), and retrospective views (comparing previous drawings with new ones and reflecting on the past). The analysis of all the images and transcripts was led by the first author, the second and third authors contributed at appropriate points.

In this case study of Jane’s pain, themes are presented longitudinally, with each theme corresponding to a time point.

INSERT FIGURE HERE

## **Results**

### **Time 1 - Two months before the PMP: crushed, overwhelmed and isolated**

The most striking feature of Jane’s first pain drawing (Figure 1, Time 1) is the heavy weight hanging over the head of the stick figure representing Jane herself. The weight is out of proportion compared to the figure; the arrows beneath it suggest it is moving downwards and will possibly crush her. The figure’s little muscles are flexed in an effort to resist. At this stage, Jane described the effects of her pain as “*confining*” and “*crushing heavy*”; the pain was greatly affecting her physically by causing even the most basic daily function to become an enormous effort.

*everything is an effort, more effort than you would ever normally need for normal things  
[...]<sup>1</sup> that’s why I’ve cut my hair off [...] it was hurting my arms to wash my hair, you  
know, things like that, things that you wouldn’t normally expect*

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<sup>1</sup> [...] indicates elision by authors of non-pertinent material



The arrows projecting from the weight towards and around the stick figure's body were an enveloping cloak:

*when you're kind of cloaked in this sort of pain, you haven't got the energy [...] you're so focussed on this [weight] [...] you're trapped in this sort of bubble of what you want to do, what you can do and what you actually feel like doing.*

By enveloping her and keeping her trapped in that position, the pain was attracting all her focus, limiting the energy required to act normally. Jane perceived a conflict between what she wanted to do and what she could do, and between what she could do and what she actually felt like doing, suggesting that the pain was also affecting her mood.

What seems to have upset Jane the most at this stage was not the physical sensation of pain as such, but rather the way it was impacting on her ability to be "normal". The expression "*things you wouldn't normally expect*" suggests a sense of surprise in how extensive the effects of pain were: as if Jane had a normative view of normality, but also of what pain should be, and the enormity of her pain was not adhering to either of these mental standards.

The first drawing also contains a line below the stick figure which she explained using a metaphor used by a counsellor many years earlier:

*"You're like a raft," she said, "and you've got all these people that you're supporting on your raft, [...] but who's supporting you?"*

This metaphor represented to Jane her tendency to assume a supportive role with people she loved and not feeling supported in return. She commented on how alone the stick figure looked:

*what there should be is other people stood next to me and there isn't*

Although she had a son, a partner and a sister who were close, they were unable to share the burden of her pain. This was compounded by Jane's resistance to ask for help, because she had been "*let down so much*".

Jane's first picture of her pain, drawn shortly after the chronic pain service referral, shows the pain as a crushing, overwhelming and isolating presence, preventing any form of "normal" life, both physical and social.

## **Time 2 - One month after the PMP: taking ownership of pain**

Jane's second pain drawing (Figure 1, Time 2) represents an ethereal human figure that seems to be patiently enduring being in chains and under attack on its lower left side.

Targets and arrows show the pain to be mostly localised:

*the pain is [...] direct in certain places [...] I can pinpoint those worse places [...] although I can pinpoint these targets, the pain then sort of blurs everything else*

Although the physical pain was localised in Jane's left hip and leg, its effects extended to the whole person, as illustrated by the outline of the figure's body. The impact

seemed reduced compared to the first drawing: the previously enormous, enveloping and crushing pain was now represented as thin arrows, which were “*blurring*” her body. The weight that was above her and ready to crush her was now below, simply holding her down. The pain was still limiting, but not affecting her whole being. Jane described the body of the figure as being “*bisected*”: one half associated with her painful past (ball and chain) while the other free half she described as her more positive “*going forward side*”.

*this half of my body is more positive [...] and that's the sort of going forward side [...] bisected in a way on that picture, but it's quite accurate*

Jane also reported a change of attitude about family support: she had started working part-time for a relative, who had helped her greatly. Allowing people to help her had been one of Jane’s learning points from the PMP:

*people that want to help you, allow them to help you, and I've been doing that*

This was a change of perspective: rather than asking for help, Jane was allowing others to help her. In terms of image, accepting help had been “*reinforcing the positive side,*” suggesting that social support had contributed to develop the pain-free positive half of the pain figure.

Jane also commented on the Christ-like appearance of the figure:

*the way I have drawn that body is almost like in a crucifixion-type pose, [...] where Jesus was unfairly tried, found guilty and punished, then I suppose that's what the pain does to us [...] We haven't done anything to deserve this, I've led a good life and been nice to people*

As a devout Christian, Jane drew a parallel between the unfair trials that lead to Jesus' crucifixion and the injustice of having to live with chronic pain. For the first time, here Jane used plural nouns such as "us" and "we", referring to chronic pain sufferers as a group. Between her first and second interview Jane had attended a PMP and bonded with other sufferers, who supported her in making important changes to her life. This feeling of pain as an injustice may have emerged as a result of the pain being more localised, allowing more mental space for reflection, and of having come into contact with fellow sufferers.

When comparing the current drawing with her previous one, Jane explained the difference in terms of the pain having been "isolated".

*I've isolated the pain, I'm not overwhelmed by everything now [...] not that it's pain-free but it's not being dragged down by the pain*

She used the noun "I" in this quote, suggesting she was feeling a sense of agency in the process of transforming her pain. This was then reinforced discussing the role of pain:

*I think at one point maybe I let the pain kind of overtake who I am, it's like when you're in a family [...] and you're mum and wife and stuff, but actually, no, I am Jane [...] I allowed the pain to take over, while actually now pain is [...] not everything, it's that bit there.*

So, with hindsight, the cloak of pain had taken over control and, with the pain being more localised, its space was reduced and could be reclaimed. Attending the PMP contributed to this process:

*[self management skills] arm you to be able to take control of everything again and move on in a positive way and I think that's why this [second drawing] is like it is, to take ownership of something and put it in its place and that's that bit [targets]*

The pain management skills acquired during the PMP allowed Jane to take back the control that the pain had been exercising and in so doing reduced the pain to something affecting only a part of her body rather than engulfing her whole being. The use of the verb “to arm” suggests that putting the pain back in its place was a battle. The end result was a more balanced view of herself, reflected in the symmetrical posture of the figure. Although pain was still present, it was counter-balanced by Jane’s new psychological resources which had enabled her to take full responsibility for self-managing it.

*because of all the changes I have made, because of the things that I have learnt, the weight on the other side is more in balance now*

By reviewing the first and second image of her pain alongside each other, she became aware of the sheer scale of the change and took pride in having had the strength to make it happen:

*I am stronger than I realise, to get from the big tonne weight and all of this to get to this now, it does take a lot of strength, emotional strength, physical strength*

In an earlier quote, Jane had compared being controlled by pain to being entrapped in a family role. The process of taking back control from her pain had been entwined with a review of her actual family role and she regained control over herself by affirming her right to do what she needed, independent of her role. This change was psychological, but also had important physical implications:

*you don't have to try to be something you are not [...] it's okay to have a bad day, it's okay to say [...] tea is not happening tonight, I am going to bed I'm afraid [...] I don't have to worry about, you know, well I am the mum here, I should be doing x, y, z*

Her perception of her family duties and her need to fulfil her role had led Jane to engage in behaviours that were damaging her physically, such as staying up rather than going to bed on a “*bad day*”; it was also by allowing herself the freedom to act according to her physical needs, that Jane had taken back control of her life and her pain.

Just one month after completing the PMP, with no change in medication and through pacing, Jane had recovered her sense of agency and felt in control of her pain, which although still present, was much more limited in its effects.

### **Time 3 - Six months after the PMP: the perils of normality**

Jane's third pain drawing is a large three-dimensional letter J, her initial, with words and names inscribed on the surface (Figure 1, Time 3). The depth of the shape is filled-

in with light red pencil and its back borders are covered in red spikes, resembling the bloody teeth of a wolf in a child's drawing. By the third interview, Jane was working four days a week and running her own home; she described her life as being full of daily chores, with the pain confined to the background:

*I have this sort of front, if you like, that I am functioning, I am going to work, I am paying the bills [...] all that time that I'm doing all this normal stuff, this is always in the background behind me*

Experiencing pain only in the background was a striking improvement compared to the previous drawings, yet, the spiky teeth suggest that not everything was as easy as it seemed. In fact, Jane described the pain as being still very present for her:

*people can't see it, which is why I've done it behind me, it's there and it is sharp, and it is all over, but people, they don't see it, because I don't whinge and I don't moan about it*

Jane was making a conscious effort to ensure that the pain would not be visible to other people and, by refraining from “whinging” and “moaning”, she was choosing to relegate it to a background position. This behaviour reflects a strongly normative view of illness that Jane had already expressed in her first interview (“*people have to take ownership of their own illnesses*”) and which she had found difficult to adhere to while overwhelmed by pain. Perhaps Jane's newly found agency had enabled her to finally put her normative beliefs about illness into practice.

The contents of the letter J offer insight into Jane's world. At the top, Jane listed the names of all the important people in her life, including her son, her sister and her sister's children. Her family were described as reliable and supportive and talking about her sister, Jane said:

*...if I need anything I can just ring her and I know she will just be there, if she can possibly be there*

With the support, however, also came the requests. Her sister had involved her in the day care of her toddler, a request that she had felt compelled to oblige:

*I can't say no, because there's nobody else she can ask [...] I'm the only person that she can ask and also that she really trusts [...] that was originally my day to just stop and do nothing*

Alongside feeling supported, Jane had again been taking on a supporting role, even though this came at a significant cost: one day a week of babysitting meant that she was working full-time.

Below, among words associated with a normal day-to-day life, Jane included “*pain-relief*” and “*rest*”, words specific to living with chronic pain, indicating that pain management was still an important concern:

*there's making sure that I get some rest, making sure I've got my pain relief [...] I'm trying to be normal, if you like, without being a sort of detriment to myself*



Jane was striving for normality and this included helping her sister where needed, yet she also knew of the risks associated with leading a normal full life. Her use of the expression “*without being a detriment to myself*” and the red spiky teeth in the background, reveal a painful awareness that it is exactly that yearning for normality that can constitute the greatest danger for chronic pain sufferers, because it can lead to excessive exertion and cause symptoms to flare up.

Social support for Jane was a matter of give and take, of balancing her own needs against those of others, which she had a history of not managing very well. Jane had learnt to accept help and rekindled a network of mutual support around her, which challenged her self-management efforts. The PMP had contributed to this process by increasing Jane’s understanding of the “*multifaceted*” nature of chronic pain:

*[it's] multifaceted, because you've got the person, you've got the pain, but then you've also got all the other effects*

Looking at all three images together, Jane summarised what she felt had been happening:

*I think working and having that sort of normal inverted commas life, allows me to put the illness in a box [...] it's always there, it doesn't control my life and all the while I'm controlling it [...] it has an effect on any problems I've got from the neck up*

The problems “*from the neck up*” Jane is referring to are her ongoing struggles with depression which she mentioned here with the intent of bringing her story to full circle.

By taking control from her pain, Jane was also able to take back control of her life and this newly acquired sense of control allowed her to keep her depression in check, a necessary condition to live a “normal” life.

The three drawings of Jane’s pain depict a positive trajectory. From being a crushing force, pain became a localised experience and, eventually, an experience she was able to hide in the background. Although each of these improvements was accompanied by a proviso to suggest the pain was still there (localised but still blurring in her second drawing and still in the background potentially ready to bite in her third one), Jane was able, in a relatively short time frame, to develop a sense of agency and control over her pain, triggering a virtuous circle that allowed her to return to lead a good and functional life and to feel in control of her destiny.

### **Discussion**

Jane’s three drawings of pain illustrate different stages in her path within the chronic pain service over almost a year. Initially, the pain was an overwhelming crushing presence, which affected her ability to lead a “normal” life and isolated her socially. As she learnt to self-manage the pain, it appeared to occupy less space in her drawings and in her life. Jane ascribed this change to having taken “ownership” of her pain, so that it was no longer controlling her but instead she was controlling it. The process had been

enabled by the PMP, where she had developed new understandings and felt supported in making life changes. Six months later, Jane's pain was relegated to a background position and she was leading a quasi-normal life. The pain was present at all three stages, but its position in her drawings changed to reflect its changing effects.

To our knowledge, this is the first longitudinal case study using IPA where visual and interview data have been combined to understand changes in chronic pain. Compared to previous longitudinal visual studies of pain, the possibility of discussing current and previous drawings at length within the interview allowed for an in-depth exploration of the meanings associated with the pain drawings.<sup>17</sup> The result is a unique subjective account of change, with findings that are relevant both clinically and methodologically. This study adopted a methodology similar to, but developing on, the cross-sectional study by Kirkham et al.<sup>19</sup> where one participant who had been interviewed after attending a PMP drew a "before and after" image of her pain, which she described as: *"a softer, gentler pain, something that I can manage."* Jane's images of pain presented in this study confirm that learning to self-manage can indeed change the experience of pain and its representation.

What was most important for Jane was not the amount of pain as such, but its impact on everyday life and on her ability to feel in control. From a state of passive endurance, where she was feeling overwhelmed, Jane acquired the psychological resources to take control of her pain and to reclaim agency over her own life. The increased sense of

control also affected Jane's depression, a co-morbid condition for many chronic pain sufferers. Deckert et al. carried out a systematic review of the outcomes reported for multidisciplinary chronic pain therapy programmes.<sup>26</sup> They found that only 9 out of 70 studies included a self-efficacy measurement, using mainly the Pain Self-efficacy Questionnaire that measures the ability to live a normal lifestyle despite the pain.<sup>27</sup> The sense of control experienced by Jane appears to be a psychologically sophisticated concept that goes beyond the ability to engage in daily tasks, making the transformation she underwent more comparable to a change in locus of control concerning her illness and her life in general, a dimension that existing measurements do not seem to capture.

Levels of pain do not necessarily change as a result of learning to self-manage, so multidisciplinary pain services focus mostly on developing acceptance.<sup>6, 28</sup> Acceptance was not prominent in Jane's narrative, although the ongoing presence of pain in her drawings could be a sign of implicit acceptance. What changed and was important to Jane was that she felt empowered by the PMP to challenge her existing relationships and make practical changes to her life, enabling her to regain a sense of mastery.

Research using visual methods allows the "inexpressible" to be discovered and assessed by participants, and experienced by viewers. It is suggested that, just as with textual analysis, researchers using visual methods should be explicit about the status they are according the images.<sup>29</sup> Although images illustrate the nature and the quality of the chronic pain experience as a phenomenon, we focused on how they were interpreted by

participants.<sup>30</sup> A longitudinal visual methodology enables both perspective and retrospective reflection, so participants can provide different interpretations at different moments. Although past images cannot elicit “stored unchanging memories”, in our experience they add an embodied dimension to memories that stimulates a new type of reflection.<sup>29</sup> For instance, given the opportunity to compare her current drawings with her previous ones, Jane’s description of her improvement became more conceptualised and she talked about developing “*control*” and “*putting the illness in a box.*” It was as if the drawings had acted as an emotional buoy reminding her of a different space and time when she felt worse and in so doing allowed her to review her experiences with increased detachment. Jane herself explained this dynamic process as follows: “*with these pictures, it’s not me telling myself, “Yes, you can get through this, you can do it.” I know I can do it, because [...] I’ve drawn it [...] it kind of brings it from your subconscious into your conscious.*” The therapeutic effect of drawing for the research already observed by Kirkham et al. was amplified by the longitudinal method because the drawings enabled Jane to develop new insights and take stock of her improvements, boosting her self-esteem.<sup>16</sup>

By focusing only on a single case, this article has offered a detailed idiographical insight into a chronic pain sufferer’s journey towards recovery. An IPA paper can be considered of good quality when the method is applied with rigour and the analysis is interpretative, well-focussed and deep.<sup>31</sup> By concentrating on a single case and

analysing each time point separately before looking across for evidence of change and continuity, we adhered to IPA's idiographical principles. This gave rise to a deep analysis of how Jane's experience with pain evolved, strongly grounded in her words and drawings, thus enhancing its validity. The case also acts as a proof of concept for using IPA longitudinally, combining visual and interview data and it sets the precedent for the method to be extended to a wider sample, to identify similarities and differences in the trajectories of chronic pain sufferers engaged in a pain management service. Current treatment rhetoric is focused on acceptance, disengaging from a battle with pain and on developing resilience.<sup>32, 33</sup> Although she did mention a battle metaphor, Jane's positive trajectory seems to have resulted more from the joint effect of having accepted her pain and of having recovered her sense of agency and control over her own life, an aspect not explicitly taken into account by current models of pain. As part of our wider study we look forward to discussing cases of patients with varied trajectories. It would also be interesting in future studies to be able to apply this methodology to investigate the experience of people with different cultural backgrounds to explore the degree of convergence and divergence experienced.

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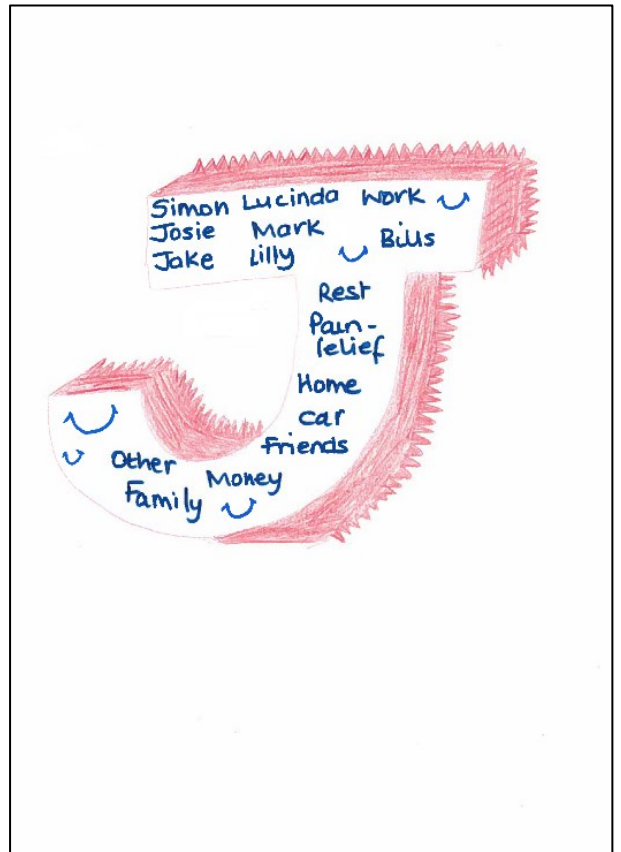
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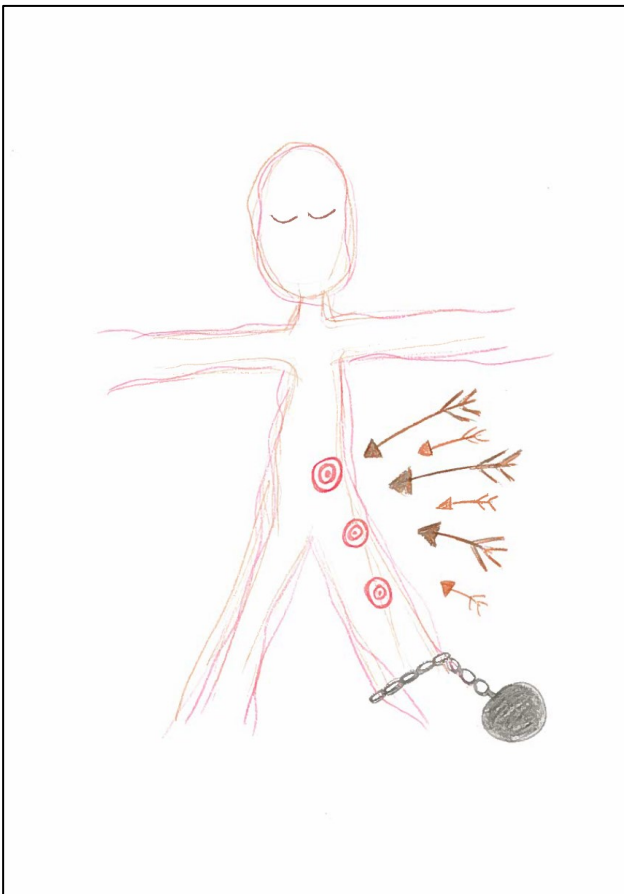




Time 1: Two months before the PMP



Time 3: Six months after completing the PMP



Time 2: One month after completing the PMP