Chapter 7

The Complexity of Persistent Pain – A Patient’s Perspective

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7.1 Introduction

For several years I thought my persistent pain story started at the time I experienced a manual handling injury, but now I know it didn’t, it started the day I was born. I thought the pain was simply explained by the physical ‘damage’ in my back, but it isn’t, persistent pain is much more complex. Before my injury, like everyone else, I experienced pain periodically, for example when I fell over, when I sprained my ankle or when I burnt myself on a hot pan. I assumed that pain meant I had physically ‘hurt’ a part of myself and that when it ‘healed’ the pain would stop. I didn’t put much thought into what pain was or what it was affected by. I didn’t need to. Following my injury, I travelled a long journey of discovery, learning about the complexities of persistent pain and considering carefully how I could use that learning to better manage my pain. This is an account of that journey.

7.2 The Injury I Haven’t Recovered From

My severe pain started on a Saturday morning in July 2008. I’d spent the previous 2 weeks helping to clear out a large Victorian house ready for some improvements. I had been doing a lot of heavy manual handling. I was told later by clinicians that it was this intensive manual handling over a short time period that likely led to my resultant back difficulties.

Shortly after breakfast, my husband and I headed off to a local beauty spot. On the journey out, I could feel my right leg starting to hurt. It was annoying, but nothing too bad, and not enough to stop us going. However, by the time we arrived home

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for lunch I was in a great deal of pain. By early afternoon I was experiencing severe pain in both my back and my leg, and I could barely walk. The pain had progressed quickly. The severe pain continued the next day, and my husband called out a general practitioner. Armed with strong painkillers I assumed that things would settle, however Monday morning saw no improvement, and if anything, the pain was worse. I was totally unable to walk, even as far as the bathroom. I phoned 101 for advice, and they called out an ambulance. I was taken by the ambulance to hospital. My L5-S1 lumbar disc had herniated and it was compressing my S1 nerve root. I was experiencing excruciating back pain and neuropathic pain. I was started on a range of strong painkillers, including morphine.

After 5 days in hospital I was discharged home. For several weeks I struggled to walk more than a few paces and I struggled to sit down or stand. Despite the powerful medication I was still in intense pain. September came around and I was determined to go back to my job as a teacher for the beginning of term. I was lucky, my headteacher was extremely supportive and allowed me to work flexibly.

7.3 Being Treated Within a Narrow View of Pain

I struggled on for many months. I was given epidural injections, very powerful pain medication, and some physiotherapy. Eighteen months after my injury I had back surgery, but unfortunately by then my S1 nerve root had been permanently damaged and surgery did little to relieve my pain. Following advice from a clinician I left the physical demands of teaching and January 2010 saw me start a new part-time self-employed life, which eased my pain situation considerably. I have never looked back.

I was given further injections, further medication and further physiotherapy. Eventually I was told there was little more that could be done for me apart from implanting a spinal cord stimulator. I was duly put on the spinal cord stimulator pathway.

For the first few years most of my discussions with the various clinicians revolved around medications, injections and surgery. I knew no different, and certainly was not adequately equipped to challenge this or move my care into something more. My pain management skills were minimal and centred mainly on managing medications. I was experiencing daily debilitating pain. The 'medical' interventions were not helping me sufficiently. Most of the physiotherapy I received had limited success for me. Although I was being given some basic advice during physiotherapy sessions, I didn't really understand why my body was constantly in pain, what the triggers for my pain were, and what the realistic likely outcomes were for me. I simply didn't understand persistent pain or how I could better manage my pain. I didn't know how to move my pain situation further forward, despite my best endeavours to do so. I was struggling day to day.

7.4 Starting to Learn About the Complexity of Pain

Around 4 years after my injury I was fortunate to receive an episode of care undertaken by Advanced Scope Physiotherapist Matthew Low. It was through this that I started my journey towards understanding persistent pain and how better to manage it.

Matt's approach was entirely different to previous physiotherapists. He focussed on improving my functional abilities and minimising my maladaptive compensation methods, which other physiotherapists had not done. He also started to teach me to understand persistent pain, and in particular *my* persistent pain, and how to manage it better. Matt demonstrated a genuine interest in both my pain story and me as a person. He used sensitive non-judgemental questioning, and carefully prompted me when needed in order to better understand my narrative. Through the sessions he got to know me as an individual and I felt valued. I felt an equal partner in my care, and I trusted him. I felt I was able to disclose anything about my pain, including the irrational fears and emotions it was causing me to experience.

Matt recognised that my understanding of pain, in particular *my* pain, was pretty low. He combined verbal, pictorial and physical explanations with suggestions for reading outside of the physiotherapy sessions in order to improve my basic understanding of pain. He skilfully revisited and extended my understanding throughout the episode of care. I entered this episode of care thinking that persistent pain was basically unidimensional (i.e. there was something physically wrong with my back at that moment in time and it was therefore responding with pain). Matt explained that persistent pain is much more complex and affected by many different things, including what I do during the day and my emotions. This learning was hugely important for me. It opened the door to me understanding what in simple terms might be feeding into my pain, and even more importantly what I could try and do to self-manage my pain. I left that episode of physiotherapy care with a much better understanding of the complexity of pain, and with much better pain management skills.

Following this episode of care, I took a personal decision to stop all medications, and to rely purely on pain management techniques. I withdrew from the spinal cord stimulator pathway. Armed with my new understanding of persistent pain I worked on minimising my stress levels, remaining positive, boosting my resilience and making adaptations to my personal life, work and home. This helped to minimise and manage my pain and I was able to live a much richer, more pain-free and more fulfilled life.

This approach to pain management worked well for several years but when my personal circumstances changed, partly through a change in my self-employment, my pain began to be more problematic for me. I felt I needed some more professional input and so I asked to be re-referred to Matt. Despite the intervening years, Matt and I were able to pick up almost where we left off. The strong therapeutic alliance we had built up together remained.

Since my first episode of care Matt had become an NHS Consultant Physiotherapist, and a key member of CauseHealth. Pain science had moved forward, and predictive processing had become a key focus for research. Whilst Matt's knowledge and skills had further improved, mine had taken a turn for the worse. I remained fully on board with the basic idea that persistent pain is complex and involves more than just the pathology that I presented with. However, during these intervening years I had heard and read various bits and pieces about back conditions, sciatica and pain, which had just served to confuse my understanding of pain, and in particular *my* pain. During this second episode of care, as well as working on the physical difficulties I was presenting with, Matt patiently took me through the basics of understanding pain once more. He also introduced me to causality, dispositionalism and predictive processing (see Low, Chap. 8, this book).

7.5 Learning About Causality and Dispositionalism

Before I could evaluate whether the concepts of causality and dispositionalism would be able to help my understanding, and management, of my persistent pain, I needed to first explore and understand them. In order to aid, and test out, my understanding of causality and dispositionalism, I created the following smallholding analogy.

The analogy is based on a smallholding commune, with individual commune members working together to benefit the whole. It considers how the individual members' dominant traits, or dispositions, dynamically vary, interact and affect the commune, sometimes resulting in a healthy commune and sometimes in an unhealthy, or unwell, commune. The way the smallholding commune works in terms of having a number of dispositions dynamically varying and interacting with one another, resulting in a healthy or unhealthy outcome, compares well to that of an individual person. Every individual person has a unique range and combination of traits, or dispositions, that dynamically vary, interact, and act as causal factors in the health of that person.

7.6 A Smallholding Analogy

Nine young friends decide to club together to buy a smallholding in a beautiful part of Dorset. Everyone will help grow food on the land, care for their animals and look after the smallholding. The aim is to have a vibrant, happy, hardworking, outward looking commune with enough food on the table, and maybe even some to sell. Each of the friends has one particularly strong trait, or disposition:

Carl – catastrophising

Henry – hypervigilance

Amy – anxiety

Debra – depression
 Sue – sleep difficulties
 Patricia – positivity
 Rebecca – resilience

Tammy has experienced trauma
 Danny has low blood pressure.

Some of these dispositions may have been present from birth, e.g. anxiety, whilst others may have been affected by their upbringing, e.g. resilience. Some dispositions may be related to their physical body, such as low blood pressure.

Each friend’s strong traits, or dispositions, vary in intensity over time, often depending on interactions with one another and what else is going on in life for them, including their physical health. Some friends have a stronger individual influence on the rest of the group than others, for example Debra is a strong influence, whilst Rebecca has a much lower influence.

Each hour, each day, each week and each month is different in the commune. One day might include Amy being highly anxious, Debra’s depression being minimal, Tammy being troubled with memories of her trauma and Rebecca’s resilience being high. On other days there will be a different mix of the friends’ dispositional levels.

The following vector diagram (see also Anjum, Chap. 2, this book) illustrates the friends’ levels of dispositions at a good time (Fig. 7.1). The dispositions represented by vectors to the left of the centre line are ‘negative’ and likely to cause the friend’s difficulty, whilst those to the right are ‘positive’.

Fig. 7.1 Dispositions on a good day

Fig. 7.2 Dispositions on a difficult day

The length of the vectors is an indication of the level of each disposition at that time. The colour of the vectors indicates the strength of their influence. The vector diagram above illustrates the friends' levels of disposition at a more difficult time (Fig. 7.2).

In such a close community, the friends will inevitably have an impact on each other. For example, when Tammy becomes overwhelmed by memories of her trauma and discusses them with Amy, then Amy may find her anxiety becomes worse. Sue may not have had any sleep difficulties for some time but as she listens to Tammy's stories, her tendency, or disposition, to sleep difficulties may become triggered. Patricia's positivity may have a beneficial effect on all the friends. It could also happen that when Tammy and Amy get together the effect of Amy's anxiety on Tammy may mean that Tammy develops a new, second disposition of PTSD (Post Traumatic Stress Disorder). This new disposition of PTSD has 'emerged' from the dispositions of anxiety and trauma.

As well as changes within, and between, the friends themselves, there are other factors affecting the friends. Some of the factors are environmental, for example whether the heating is working or not or whether there is a storm outside. Some may be financial. A bill for repairs to the roof may have come in or some money may have been left to the friends in a will. Some may be social. One of the friend's family may be causing difficulties or the neighbours may be upset by their barking dogs. Some may be biological. Some of the friends may have become unwell with a virus.

All these factors will affect the friends differently. For example, Amy may become anxious over financial concerns and Sue may find it difficult to sleep when there is a storm outside. At such times Rebecca's resilience may reduce.

When everyone is at their best, the heating works, the weather is good, the friends have enough money, their families are supportive, they have no extra physical ailments and they are working well together the 'health' of the commune is good. The commune is 'healthy', and the friends are happy and contented. At this point the group of friends could be considered to have developed a new disposition, that of being a community of mutual support. This mutually supportive community may well provide positive benefits to its members. For example, Carl may benefit from the support of the commune and cease to be hypervigilant in that environment. If Carl moved out of the commune then he may be able to maintain this benefit, for at least a period of time. However, if he then moved into a more dysfunctional community, then this hypervigilance would likely return.

Life isn't always good for the commune, though. As the friends vary, including for example Amy becoming more anxious, Catherine catastrophising and Debra's depression becoming more prominent, then things might start to get a little harder for them. The commune becomes less 'healthy', although outwardly it may still appear to be fine, the friends may still be reasonably content, and the commune may still be functioning.

Unfortunately, at some point in time the commune may cross a 'threshold' and become 'unhealthy' or 'sick'. It is impossible to predict what combination of the friends' levels of dispositions might cause this to happen. The threshold could be crossed due to a combination of Amy experiencing high levels of anxiety, Sue having substantial difficulties sleeping, Debra suffering moderate levels of depression and Rebecca's resilience being unusually low. However, it could be crossed due to a completely different combination. No one friend in isolation is likely to cause the threshold to be crossed, it is the novel mix of their levels of dispositions at that moment in time that causes this.

It may be that the commune oscillates around the threshold, being 'healthy' at times, and being 'unhealthy' and struggling at other times. I find it useful to represent the interactions of the dispositions as a circular vector diagram. The diagram in Fig. 7.3, based on the vector diagram above for a good day (Fig. 7.1), represents the 'health' of the commune on that good day. Each oval is a representation of the strength and level of each friend's disposition. Dispositions within the circle are negative, whilst those outside the circle are positive. The dotted circle is a representation of a dynamic 'threshold' which shows the commune's 'capacity' for health. The higher the level of positive dispositions, the bigger the 'capacity' of the commune to be healthy.

The diagram in Fig. 7.4 is based on the vector diagram for a difficult day (Fig. 7.2) and represents the health of the commune on that particular difficult day. We see that the representation of the dispositions crosses the capacity 'threshold', which is now smaller than it was on a good day.

As the commune becomes 'unhealthy' or 'sick' it starts to struggle. Everything becomes harder and some of the friends' individual traits may worsen. This serves

Fig. 7.3 A dynamic threshold for health

Fig. 7.4 Threshold on a difficult day

to maintain the unhealthy situation, maybe even making it worse. The circle, or threshold, is smaller this time, in line with the levels of the positive dispositions being smaller, and so the ‘capacity’ of the commune to be healthy is reduced.

Once the commune has crossed over the threshold and become ‘unhealthy’ or ‘sick’ then it can be difficult to improve the situation and get it back over the threshold to become a healthy commune once more. There is unlikely to be a quick ‘fix’. There is unlikely to be a single ‘cause’ that can be addressed in isolation in order to fix the problem. For example, just a clinician supporting Debra to improve her depression may not have enough of an impact on the overall complicated mix of the

friends' dispositional levels and therefore the commune. It may also not be effective without addressing, for example, the commune's financial difficulties at the same time.

Improving just one friend's dispositional level is unlikely to improve the mix enough to bring the commune back over the threshold. Attention needs to be paid to the multiple factors, or causes, including both the friends' dispositional levels and the external factors, such as finances, social relationships etc. that impact on them. Professional input could be helpful in addressing the variety of factors. For example, support in resolving financial difficulties, support with depression or support with any medical conditions such as low blood pressure. Advice could be given to help support the commune self-manage their situation more effectively. As well as trying to reduce the levels of the more negative dispositions, such as Debra's depression and Amy's anxiety, then boosting the more positive dispositions could help the group. For example, boosting Patricia's positivity might help 'lift' the group. Supporting all the friends, in a variety of different ways, will give the best chance for the group to rise back above the threshold and become a healthy, happy, productive commune once more.

7.7 The Analogy Explained

We all have a unique set of traits, or dispositions. An individual's dominant traits, or dispositions, might be, for example, anxiety, hypervigilance, catastrophising, depression, sleep difficulties, positivity and resilience. That individual may also have experienced trauma and have low blood pressure. These dispositions will vary and interact, as they did in the commune.

In the same way these dispositions were affected in the smallholding commune by external factors, such as unexpected bills or social problems, they will be affected within an individual. For example, an impending court case might cause an individual's anxiety levels to rise, or a break up with a partner might cause depressive levels to rise.

Sometimes, a specific mix of the relative strengths, weaknesses and interplay of these dispositions may cause that individual to cross a 'threshold', which is unique to that individual, and they may become unwell. The individual's unique genetic makeup, existing health and health dispositions will be factors in the presentation of their illness. For example, at any one time, one individual may be pre-disposed to suffering Chronic Fatigue Syndrome, whilst another may be pre-disposed to suffering a chronic pain condition, or generalised anxiety disorder or maybe shingles.

This doesn't of course mean that individuals who are happy, stress free and who have few outside pressures do not become unwell. One of their dispositions, or causal factors, may be physical, for example in my case I have a damaged S1 nerve root. This factor may be very dominant, either in short bursts, or for extensive periods, so causing the individual to cross a threshold, in my case of pain, for either a short or long period of time. Although this factor may be dominant, all the factors still vary and interact together, giving a varying experience of pain and wellness.

In terms of recovery, or improvement, in the same way that the causal factors associated with the smallholding commune becoming unhealthy are complex, so it is with the individual. Trying to address one factor alone is unlikely to improve an individual's situation enough to allow them to cross back over the threshold and return to good, or better, health. A wide-ranging approach is needed. This might include the need for mental health support, GP support, counselling, peer group support and social support.

Crossing back over that threshold and returning to good, or better, health is not always easy. Perhaps the most important first step for that individual is to understand that there are many causal factors involved, which dynamically vary and interact with each other. These causal factors ideally need to be supported and addressed together.

7.8 Combining Causality, Dispositionalism and Predictive Processing

I currently mainly suffer from neuropathic pain, caused by 'damage', and ongoing irritation, to my S1 nerve root. I wanted to know how the nerve signals being generated from this nerve root, often spuriously, might be processed in me as pain and so, with Matt's help, I sought to understand the predictive processing model of pain. Fundamentally the predictive processing model of pain considers peripheral sensitisation, and looks at how anxiety, emotion, expectation and attention may change and impact pain. With the help of Matt, I was able to combine the basic concepts of causality, dispositionalism and predictive processing to come up with a simple understanding of MY pain that works well for me.

7.9 A Simple Understanding of My Pain

I have in my mind/body a 'model' (predictive model) which informs me as to whether to give an experience of pain or not, in a variety of circumstances, based on presenting factors. When a part of my body, in this case my damaged S1 nerve root (which may be being irritated by, for example, position, load or temperature), emits an 'impulse', then my predictive model considers this factor, along with other factors, to evaluate whether to give an experience of pain or not. These factors include my current novel mix of the levels of my traits.

I have a number of personal traits, or dispositions, which vary over time. For example, I have a tendency, or disposition, towards anxiety and poor sleep. I am naturally positive and have high resilience. I experience interaction between these dispositions. For example, my sleep is likely to be worse when I am anxious, and my resilience is likely to be reduced when I am sleep deprived. Some of these

dispositions have a stronger influence than others on my presentation, for example anxiety and poor sleep have a greater impact on me than positivity. I am also affected by external factors. For example, my anxiety will increase if I experience work place bullying or an unexpected household bill, and my positivity will increase whilst experiencing success. I have an ever-changing novel mix of the levels of my dispositions. At a 'good time', my anxiety might be low, my positivity high and I might have had good sleep. At a 'bad time', my anxiety may be high, my resilience low and my sleep poor.

My predictive model 'knows' what combination of dispositional levels and other factors, including the impulse from my S1 nerve root, are likely to be 'ok' and don't need a response of pain. If the combination of factors at a moment in time, including the 'impulse' from my S1 nerve root (which is likely for me to be a dominant factor), matches the predictive model of being 'ok', then no action is taken, and no pain emerges. If not, then pain emerges to alert me to do something to stop the irritation on the S1 nerve root continuing. Changes in the novel mix of my dispositional levels, and my S1 nerve root impulse, may, or may not, be sufficient to change whether I experience pain or not.

My experiences inform my predictive model. These experiences might result in the predictive model being changed. In order to improve my pain situation, then I would need to work on optimising my personal factors, e.g. anxiety, sleep, resilience and positivity, my physical factors, e.g. S1 nerve root irritation and also external factors, e.g. temperature, finances and work conditions. This is because my predictive model takes the combination of these factors into account when deciding whether to give me a pain experience following an impulse from my S1 nerve root. Improving one factor only is unlikely to bring about sufficient change.

7.10 How Has Understanding Pain in This Way Helped Me?

Understanding pain has been hugely important to me in terms of my learning to manage my pain situation and lead as full and fulfilled a life as possible. Having a narrative in my head about what is likely affecting my pain and what is happening with my body, which I can fully identify with, is very important to me. It provides me with the confidence to try different things, cope when I am experiencing a flare of symptoms, work out different ways of doing things in order not to 'wind up' my condition and generally live well despite living in pain.

Although important, on its own this understanding isn't enough to successfully manage my pain condition on a day to day basis. I need to use this understanding to seek ways to manage and improve my condition and continue to live as well as possible.

In overall terms I view my pain management situation as needing to reduce the physical irritants on my S1 nerve root, and to optimise my personal, social, health and emotional factors. I also need to consider, and hopefully address, any negative thoughts, beliefs and past experiences which might be acting as factors in my pain

Fig. 7.5 Mind map illustrating the complexity of my pain

experience. As part of this I need to recognise, and hopefully improve, any negative dispositions I have, such as anxiety, and build on my positive dispositions, such as my resilience and having a naturally positive outlook.

I created a mind map (Fig. 7.5) to highlight the areas I need to attend to if I want to live as pain free a life as possible.

The mind map is complex, reflecting the complexity of pain. There are some S1 nerve root specific elements, for example using soft cushions when sitting, keeping my right leg warm etc. There are also elements that are more general, for example good sleep hygiene, enjoying good friendships and reducing anxiety.

It is hard to address all these factors at the same time when trying to improve pain, and it is hard to work out whether the measures you are taking are having a positive impact on your pain, or not. In order to provide a focus for improvement, and to track my improvement, I decided to use the idea of vector diagrams. The vector diagram in Fig. 7.6 shows factors I identified as being the main contributors and improvers to my pain experience in January 2018. The length of the vector gives an indication of the ‘size’ of the factor, as I saw it at the time. The red vector at the bottom gives an overall indication of the ‘size’ of all the pain contributors combined, and the green vector at the bottom an overall indication of the ‘size’ of all the pain improvers combined. The aim is to decrease the pain contributors and increase the pain improvers as much as possible.

The diagram in Fig. 7.7 shows how I rated the same factors in August 2018. Notice that there are some elements I have been able to change, but some that have stayed static. More work to do!

Using vector diagrams works well for me. They give me an instant visual indicator of the problems I have chosen to work on, and I can see visually whether I am making progress with those elements or not, and how much progress.

In my experience clinicians put more emphasis on negative pain factors, the pain contributors, but I think it is helpful to put an equal emphasis on positive factors, the pain improvers. When you are in pain it is far too easy to focus on the negative. I find putting an equal focus on positives really helps to take control of my pain situation and move it forward.

Fig. 7.6 The main contributors and improvers of my pain in January

Fig. 7.7 The main contributors and improvers of my pain in August

7.11 The Complexity of Persistent Pain

During the first few years following my manual handling injury I was treated predominantly, if not solely, within a ‘medical’ model. I had no understanding that persistent pain was complex, and looked only to physiological factors, medications and surgical interventions. I struggled badly with the pain I was experiencing and had few pain management skills.

Following interventions by physiotherapist Matthew Low I was introduced to an understanding that persistent pain is inherently complex. Through my understanding of causality, dispositionalism and the predictive processing model of pain, and with Matt's help, I have been able to come to a much better understanding of pain, and in particular *my* pain. Understanding that persistent pain is inherently complex has enabled me to develop my pain management skills, focussing them on a wide variety of causal factors.

Good understanding and good pain management has enabled me to lead a much richer, more pain free and more fulfilled life.

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