

“The difference between being looked at and being seen”:

An in-depth consideration of experiencing the
Whole Person Therapeutic Approach for chronic illness

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Abstract

The Whole Person Therapeutic Approach (WPTA) is a non-dualistic, person-centred clinical approach to healthcare. Clinicians who operate from this approach hold a unified ontological assumption that subjective and intrinsically individual “mind” elements, such as psychological factors and lived experiences, are all relevant and potentially important factors in the progression of physical disease from onset to recovery. When treating, WPTA clinicians explicitly attend to the whole person including their unique life story as potentially important in treating the presenting symptoms.

Using Interpretive Description methodology (ID), this doctoral research provides an in-depth consideration of how interpreting the experiences of persons who suffer from chronic conditions, and who were treated by WPTA clinicians, could inform the care for chronic conditions more generally. A two-phase study was carried out. In phase one, secondary analysis of four segments of video interviews and seven transcripts of interviews were analysed. In phase two, semi-structured interviews were carried out with 18 people seen by WPTA clinicians in mainstream healthcare settings. A purposeful sampling approach was used to recruit 10 participants from an immunology day clinic at a large tertiary hospital, and eight participants from two physiotherapy clinics.

Four themes were constructed from the data. Theme one, **seeing patients as persons and explicitly acknowledging their unique illness history**, captures the importance of feeling acknowledged for one’s personhood. Theme two, **clinicians bringing relevant aspects of their whole selves into the therapeutic encounter**, captured how participants experienced the subtle negotiation of professional identities, clinical expertise and boundaries undertaken by clinicians within the therapeutic encounter. Theme three, **negotiating first encounters**, focused on participants’ need to feel listened to and truly heard, before they engage in the WPTA process and to *allow* WPTA clinicians to gain access to their *whole*. The last theme, **a door into understanding**, attempted to capture the essence of what the WPTA experience meant for the participants.

This research captured the essence of participants’ experience of “*being seen rather than being looked at*”, which appeared to be a critical component of care. At its core, it

is experienced as being acknowledged for one's personhood within a therapeutic encounter. Through explicating the subtle and profound ways clinicians achieved this, this research makes significant contributions to knowledge with respect to the ways clinicians can co-construct patients' readiness to enter into any type of therapeutic relationships. Further, this research is the first to identify the profoundly humanising and transformative educational experience of WPTA from the perspective of the person being treated. This has implications for clinical practice, and clinicians' education. The findings of this doctoral research can serve as a base for shifting research focus from the individual patient as the sole active agent in their experience of chronic illness to exploring the role relationships with care providers play in this adaptation and therapeutic outcomes. This research also demonstrates the insights that can be gained through attending to the impact of clinicians' implicit ontological assumptions about the nature of health and illness, on the care experience of patients.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgments), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Galia BarHava-Monteith

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Ethics Approvals

Ethical approval was obtained from:

- AUT University Ethics Committee (15/358) on 24 November 2015
- Auckland District Health Board (A+ 7005) on 11 December 2015

Transcription Guide

<i>Italics</i>	Marks direct quotes
... (<i>pause</i>)	Indicates a pause in the participant's speech
...	Indicates words removed from the original transcript
[]	Indicates words added by the researcher to clarify meaning
' '	Indicates a quotation within the participant's direct quote
“ ”	Indicates direct quote from a participant or literature when less than 40 words, or to highlight a new expression or particular use of a term (e.g., “co-emergence”, “mind”)

Presentations Arising From This Research

BarHava-Monteith, G. (2017, June). *The difference between being looked at and being seen*. Presented as part of Professional Development to the Immunology Department, Auckland Hospital, Auckland, New Zealand.

BarHava-Monteith, G. (2017, September). *The difference between being looked at and being seen*. Presented at the New Zealand Rehabilitation Conference, Christchurch, New Zealand.

BarHava-Monteith, G. (2017, October). *The difference between being looked at and being seen*. Presented at the ASCIA Conference, Auckland, New Zealand.

BarHava-Monteith, G. (2018, February). *Being looked at and being seen – The patient's perspective*. Presented at the ASCIA follow-up professional development presentations, Auckland, New Zealand.

Chapter 1: Introduction or why this PhD?

1.1 The purpose of this research

The purpose of this research is to explore and examine the insights of people with chronic conditions, who have experienced both standard biomedical care and the Whole Person Therapeutic Approach (WPTA) in the context of modern Western medicine (Lindsay, Goulding, Solomon, & Broom, 2015). Clinicians who follow the WPTA operate from a unitive or non-dualistic view of persons in which mind and body dimensions are not kept separate. Amongst other considerations, they argue for a “co-emergence” model of human physicality and subjectivity. This gives rise to a concept of disease aetiology which assumes that subjective and intrinsically individual “mind” elements, such as psychological factors, personal history and experiences, are all relevant and potentially important factors in the vulnerability to, onset of, and perpetuation of physical disease. WPTA clinicians consider that attending to these subjective elements is crucial to the treatment of all diseases (Broom, 2007).

These clinicians prescribe medication and other biomedical treatments as required. They also include and attend to the person’s “story” and personal meanings ascribed to those stories, because of their conviction that “mind” factors and meanings that are highly specific for the individual usually play some role in the presenting disease (Broom, 2016b). The co-emergence model necessitates that medical practitioners attend to the person and their disease as a whole. It requires clinicians to have the capacity to create a clinical space where persons are able to convey their stories (Broom, Booth, & Schubert, 2012). The theoretical base of the WPTA is outlined in more detail in Chapter 2.

Using Interpretive Description methodology (ID), the current research explores how considering and interpreting the experiences of persons who live with chronic illness, and who were treated by WPTA clinicians, could inform the clinical care approach for chronic conditions more broadly.

This research is a very personal project, emerging from my own experience with chronic illness and the WPTA. It could be argued that my subjective interest and personal investment in the research topic introduces the potential for bias. Researchers’ reflexivity is said to be integral to the overall quality of any qualitative research as it speaks to notions of authenticity and genuineness, demonstrated by the researcher’s

honesty and transparency about their own position towards the study at the outset of the project and throughout (Tracy, 2010). Therefore, one purpose of this chapter is to introduce the background for this research and explicitly articulate the assumptions I made at the outset of the project, in an effort to make them transparent. In the current study, I also endeavoured to weave a number of reflexive practices throughout the research process.

I came to view reflexivity as a multidimensional practice comprising three key aspects. The first is explicit acknowledgment and identification of the researcher's place and presence in the research at the outset of the project (Thorne & Darbyshire, 2005). This may begin with a researcher explicitly identifying the preconceptions they brought into the project, which could include personal and professional experiences, pre-study beliefs about the research question, as well as theoretical foundations that guided their thinking (Malterud, 2001). Put simply, this first aspect is concerned with being up front about one's own position.

The second aspect is ongoing critical examination of the research process regarding how these preconceptions, as well as other relevant personal factors such as gender and culture, might impact on the project, from deciding whom to involve, how they should be involved, what should be asked of them and how the data are analysed (Underwood, Satterthwait, & Bartlett, 2010). As well, researchers need to be explicit about how their own thoughts, feelings and behaviour might influence others (such as the participants) (Clancy, 2013); that is, being transparent and reflexive in the *process* of undertaking the research.

The third aspect is concerned with the thesis or written report. Tracy (2010) suggests reflexivity should be woven throughout the report so the reader can decide for themselves the extent to which the researcher was authentic and genuine with respect to attending to their own position. It is about *showing* rather than *telling* the reader that the researcher embedded those practices (Tracy, 2010).

As such, the primary aim of this chapter is to describe some of the relevant parts of my life and my own experiences of health, ill health and biomedical treatment. The reflexive parts of this chapter were written prior to the research taking place, to help capture my assumptions at the outset of the research, though I have subsequently edited for clarity, and indeed commented in the discussion on how my insights were deepened, challenged and changed through undertaking the research. I have kept the use of the

future tense in the following section, given it was written between May 2014 and August 2015, prior to data collection.

1.2 Reflective positioning: Chronic illness as a process of biographical discovery

I endeavour to reflect on my own comprehension and interpretation of my experiences, before embarking on my research, so that I am able to acknowledge those when interpreting the interviews. I have selected experiences from the pre-diagnosis stage, diagnosis and biomedical treatment, as well as my own experience of the WPTA method. I will try to articulate my own interpretation of these experiences before hearing those of others. These experiences, episodes and interpretations have been integral to my decision to pursue a PhD, and indeed to pursue *this* PhD.

1.2.1 Before diagnosis

I always saw myself as a strong woman with a highly developed sense of self-efficacy. I was a firm believer that I could do whatever needed to be done in any given situation. I migrated to New Zealand from Israel in 1992 after meeting my husband while backpacking and tramping throughout the South Island. I undertook my graduate and postgraduate studies in Psychology at the University of Auckland. Upon completion of my master's degree, I entered the business world, where I worked for some of New Zealand's leading companies in a range of senior executive roles.

As an adult, I have had many health challenges. These include adult onset of asthma, unexplained bleeding from my bowel and bladder, challenging allergies and a diagnosis of endometriosis, which resulted in surgical treatment. Following the birth of my first child, I also suffered from acute mastitis that had to be drained using semi-surgical extraction methods. Despite all this, I viewed myself as a healthy and agentic woman. Reflecting back, this could have been partly because of my successful career in an intensive business environment, where I was rewarded for being seen to be confident and "tough-minded".

There was no cancer or any other chronic illness in my family. In addition, the messaging from my environment, especially from my then local family doctor or general practitioner (GP), was that my various ailments were merely a case of the "worried well and affluent middle classes", perhaps because so many of them (the bleeding, for example) had no clear explanation or diagnosis. As a consequence, having these health issues felt very confronting to how I saw myself. I was almost ashamed by

them – I saw *them* (my health issues) as external factors shaming me and I treated *them* as a “nuisance”.

I soldiered on through my ill health by eating well, exercising plenty, doing yoga, practising meditation and restricting my intake of all things unhealthy. In short, I was a firm believer that my health was under my control, and that if I took responsibility and lived a healthy lifestyle, I would be healthy.

Although I viewed myself as a “very well woman”, an astute and careful outside observer, questioning me carefully about my health, would have probably challenged that. But this never happened. I would get very sick from simple infections and take a long time to recover. I suffered from persistent allergies that seriously compromised the quality of my life. Nonetheless, I was able to achieve a lot and I, and those around me (family, friends and the medical practitioners I frequented), never, ever, considered that there might be an underlying illness and that, in fact, my health was seriously compromised.

1.2.2 Diagnosis

In October of 2010, I participated in a fundraising initiative to raise money for the homeless in Auckland, which involved sleeping outside for a night. Over the course of that night I observed my legs swelling up, until in the morning I could hardly walk. What ensued was a rapidly cascading course of events. Taking control over my own health, I stopped seeing the local GP who dismissed my health concerns and returned to my previous (pre-children) GP, who I perceived to be more careful, thoughtful and astute. That GP referred me to a specialist physician immunologist. This specialist did indeed treat my symptoms very seriously and once I started experiencing nerve damage in my feet, I was admitted to hospital to undergo exploration for a differential diagnosis. It was at this time that I was diagnosed with early stage three Churg-Strauss Vasculitis (CSV).

I chose to include the following sections from my clinical notes to give the reader a “taste” of how the patient (myself) was described in a biomedical diagnostic process:

12/10/2010 (First consultation)

On examination the patient was a pleasant, fit-looking woman in no distress. There were no abnormalities of the cardiorespiratory systems. She was noted to have mild pitting oedema of the lower limbs. ... She was noted to have postural

lesion on the right upper limb. Scarring was also noted. ... Vasculitis would probably explain all of these symptoms and the blood tests will be helpful in regard to this.

2/11/2010 (Third consultation)

She has developed a numbness of the heels. She also has a lesion on the back of the neck. I have suggested admission to exclude Churg-Strauss Vasculitis. I have arranged for her to be admitted to Auckland hospital for further investigation.

12/11/2010 (Fourth consultation)

The biopsy has shown she has Churg-Strauss Vasculitis. She will commence pulse methylprednisolone and pulsed cyclophosphamide. I have commenced her on 60mg prednisone. She is on calcium supplements. She will need a bone mineral density assessment. She will be seen shortly.

1.2.2.1 Churg-Strauss Vasculitis (CSV)

CSV is a rare and very serious disease or disorder reported to have the prevalence of 0.11 to 2.66 new cases per million population per year. It is most commonly described as a 3-stage disorder. The first stage is (usually) characterised by adult onset asthma, with rhinosinusitis and nasal polyposis. This is followed by a second phase where eosinophilia is present in the blood and persistent skin eczema-like rash. The third and final stage is described as “a properly defined, vasculitic phase.” (Baldini, Talarico, Della Rossa, & Bombardieri, 2010, p. 528). In the third stage, CSV may cause injury to many organ systems and may damage small- and medium-sized blood vessels. It is a serious disease that can be fatal if it is left untreated. However, because of the rarity of the disease, it is difficult to cite definite mortality rates (Solans et al., 2001). Shiel (2014) suggests that CSV can be brought under control with aggressive treatment and monitoring where remission is possible, especially if there is no severe organ damage.

1.2.2.2 Biomedical treatment

Once my diagnosis of early stage three was confirmed, I was prescribed treatment that, according to my lead specialist, followed the Federal Drug Administration protocol for the treatment of stage three CSV. The treatment included infusions of corticosteroids and immune-suppressants, namely, cyclophosphamide (CYC) (Solans et al., 2001). I was told that this treatment would considerably improve my prognosis and my overall survival rate by controlling the disease manifestations if promptly administered, in line

with evidence-based research into this disease (Baldini et al., 2010). Indeed, the treatment was extremely successful and my symptoms were brought under control within months.

However, all that I knew about myself was transformed overnight on November 12th, 2010, and I came to see myself as chronically and, potentially, lethally sick. The transformation, from a driven woman who saw herself as strong and in control, into the object of a sick person, was already underway. In the weeks leading to the final diagnosis of stage three CSV, I encountered specialists who spoke only to my husband, who referred to me, with myself present in the room as “her”, who only studied my chart and never made eye contact. I felt as if everything I was, and had achieved to that point, no longer mattered. I felt, and was in fact, objectified and reduced to a disease, to a collection of cells. My humanity, my agency and my voice were irrelevant. They were abolished by the biomedical system I encountered. Only the results of my skin biopsy and my blood tests appeared to matter.

As I engaged with the academic literature in preparation for this PhD, I have come to interpret my experience of being diagnosed with CSV as a biographical disruption (Bury, 1982; Charmaz, 1983). Just like that, everything I had taken for granted about my life and all my knowledge about myself was profoundly and irrevocably disrupted.

In many ways, I welcomed the very biomedical experience. As Bury (1982) described, in his seminal article on the notion of chronic illness as a biographical disruption in a study of patients with rheumatoid arthritis, I welcomed being *properly* diagnosed. I found it a legitimising experience because I felt that, finally, significant people in my life would now see me as legitimately physically sick. Not as a neurotic, affluent, health-obsessed white woman. I was also full of hope that I would now receive the treatment, which would *fix* me. This was exactly the reaction I did receive by-and-large from everyone around me. At the beginning, I experienced unadulterated levels of support and willingness to help, empathy and concern from my family and none of the stigma associated with mental health conditions such as depression I have seen others experience.

The cost of the treatment was enormous for me as a person. I no longer recognised myself. I was a weak patient; there were many occasions when I could not face the world because of my altered appearance, I was always afraid of how people would react to me. I also felt like I could not *really* talk to anyone about my experiences.

Nonetheless, throughout the treatment, I worked hard not to succumb to the sick role; I did my best to preserve the daily routine of a family environment for my two children, then aged six and eight. I cooked as much as I could and tried to accompany them to school events if I was up to it and invited their friends over.

As time progressed, perhaps two to three months into the treatment, I felt that some people did not know how to talk to me and others expected me to get better and once again go back to the agentic, energetic person they saw me as. I continued to work, but in a much-reduced capacity, and did not work during the chemo weeks. In speaking with others diagnosed abruptly with a serious disease, I came to realise that the behaviour of other people in your life can be a source of tremendous support but also tremendous heartbreak. For me, a way to make sense of these altered relationships and to cope with their impact, was through writing on the website I founded in 2007, as in the following extract:

I am being treated right now and the treatment itself is dominating my life at the moment; it includes both steroids and chemotherapy. I am told that I should go into remission and that my prognosis is as positive as can be. Be that as it may, this turn of events is certainly a game changer, or as the Yiddish saying goes:

‘Man makes plans and God laughs’

I spent a lot of time processing this turn of events so as to deal with these changes for myself, my family, my career and my business as best I could. I thought about blogging about it, but blogging is a daily thing, and I didn’t feel it was the right vehicle for me.

What I do have now is more time: time to think and to really work through ideas in my head. The deep thinking has certainly helped me make sense of things (BarHava-Monteith, 2011)

1.2.2.3 Questions, questions and more questions

Following the treatment, when I was told how well I was responding and that mortality was unlikely from the CSV, I still had many questions; both practical and existential. Questions such as what caused the CSV? How long had I actually been sick? Was it genetic? Do my children need to be tested? Was I going to survive this without having organ damage?

My questions mirrored many of those of other people who experienced a diagnosis of life-limiting conditions (Williams, 2000). These questions were mainly greeted by rather evasive and vague answers by my biomedical team, or by a simple, “I don’t know, but the bloods are looking good and that’s all we can go by”. The positive results following the treatment were all we could cling to, and fortunately for me, I responded remarkably well to it. The disease came to a halt; the blood tests were looking good.

10/2/2011

She has been struggling with the cyclophosphamide. The last infusion was better. ... She continues to have slight numbness of the legs. There is no sign of Vasculitis. ... she will be seen in a month.

Even though my blood results kept improving, I felt like the questions became even more difficult for my biomedical team to answer. My questions were now about meaning - what does it mean to live with a chronic and unpredictable condition for the rest of my life? Will I ever be able to live a full life again? Will I be able to work to the level I used to? Will I always have to be fearful of symptoms and changes in my body?

To manage my ongoing anxiety, I drew on my expertise as an executive coach who worked from the framework of “Positive Psychology”, I practised yoga, meditation and wakeful mindfulness. I also undertook to practise gratitude with my family (Peterson, 2006; Seligman, 2002). I described this phase in my pre-assumptions interview with Professor Liz Smyth before undertaking my research in May 2014:

I did all of that, I did mindfulness, I do yoga, I did three good things a day, and I did everything. But it wasn’t enough. It only dealt with the anxiety when I was doing it but then I was left with it [the anxiety]. Despite the promising reaction to the treatment and my physician’s reassurances, I was full of fear that the CSV might just return. The illness felt like a “monster” just hiding in the shadows and that anything might trigger it. Any changes in my physical body or any strange physical sensations would send me into a hyper anxious mode thinking “it was back”. I felt I had no control over “it” and that the CSV was just waiting in there like it did for so many years without my knowledge. I also continued to experience haematuria, as well as difficult side effects and painful reactions to various treatments. My anxiety persisted throughout, and I tried to raise how anxious I was feeling, despite responding so well to the treatment, with my clinical lead. I was not satisfied with the “the bloods are looking good”

response and was eventually referred to see an immune specialist who operated from the WPTA. My lead specialist felt that he would be able to help me with my questions and to help me overcome my quite severe anxiety.

15/9/2011 (Clinical notes)

After discussion, she will be seen by Dr X for a mind-body approach. Galia is understandably very worried about the possibility of a relapse of the CS Vasculitis.

At the time I was quite clear I was only going to see another specialist, not a mental health professional, despite being a trained psychologist myself. I was very attached to the fact that all the symptoms I experienced for many years could now be attributed to a real illness – not a psychosomatic, “lesser” form of illness. I was very angry at the prospect of being told it was in my head. It certainly felt like only a physician could understand what I was physically going through.

1.2.3 WPTA process to health

My first experience of the WPTA was unsettling and almost painful. I found it very destabilising and distressing being confronted with the possibility that, in fact, my own life story might have something to do with this very real illness. I remember that feeling vividly, because to me this implied that my CSV was a psychosomatic illness, which therefore undermined its legitimacy. And yet, it felt very right. It felt right because the WPTA medical practitioner asked me in that first meeting what no other medical professional had asked me before. He asked me the most crucial questions about my history. It was in answering those questions, in the very safe environment he created, that I realised that my history and my life’s story had to be connected with the illness. Despite my resistance, I felt that I was ready to embark on a daunting journey of self-discovery and self-confrontation to be truly well again.

While undergoing chemotherapy, I felt that I was doing everything I could to deal with the day-to-day reality of managing the treatments. I also felt that my extensive knowledge of Positive Psychology was providing me with enough tools to deal with my reality. It was only once the chemo and intensive steroid therapy were over and I was on a pill regime and starting to think about bringing my life back to a “normal” space, that I knew that I needed to rethink everything so that the disease will not come back.

Entering WPTA therapy was like entering a long and very dark and quite scary corridor into the unknown. Growing up in a family that had both biomedical and mental health professionals in it, psychosomatic illness was very much seen as a lesser kind of illness that can be attributed to weak character. I, on the other hand, was always described by people around me as strong, especially in referring to how I was dealing with my illness. They said to me that it was through that strength, that they were all certain I would emerge, stronger, better, smarter, on the other side.

Very quickly in the WPTA process, I came to realise how much of my being was built on dualistic assumptions. If I was strong then I could never be weak. If I was a fighter I could never be a victim and so on and so forth. I spent much of my life leading up to the diagnosis suppressing what did not fit with those notions. The WPTA experience for me was one of unification, that I can be simultaneously strong AND weak, and that my illness was in fact inseparable from my own personal story/history.

The WPTA process itself was set in a psychotherapeutic setting. I have experienced similar environments in the past, but even though there were superficial similarities, it fundamentally felt very different. This was the first time I actually felt it was safe to bring the whole of myself into the therapeutic environment, mind, body, history, and spirituality. This was the first time I really felt I was listened to and approached as a whole person. Below is an extract where I described this feeling in my pre-assumption interview:

The first time I was sitting with the therapist in the assessment [to decide] if he would decide to take me on, I could just breathe. I felt that I was with someone who just gets that it's me this whole person, it's not just in my head, not just in my body, not just the blood cells. I am a whole person. (May, 2014)

The combination of undergoing the WPTA process in conjunction with the biomedical treatment was an unmitigated success in terms of my prognosis. The physiological results were quite outstanding. My eosinophilia was under control when I started the process, but I still experienced unexplained bowel bleeds and there were high levels of blood in my urine. These bleedings were so severe that my lead specialist sent me to have a colonoscopy and cystoscopy to investigate them during my chemo treatment, but found nothing. Once I commenced with the weekly WPTA meetings, which lasted for approximately 16 months, those bleedings virtually ceased and I have not experienced them since.

Throughout the WPTA treatment, I still had to cope with the side effects of the oral steroids and chemo drugs, which I found very distressing. However, because I was working with the WPTA physician, my lead immunologist felt that I could come off the medications sooner than he anticipated. This, in itself, was a major contribution towards my ability to resume my life, and minimise the long-term side effects of the medication. Most CSV patients remain on low-dose maintenance medications for lengthy time periods as, despite much advancement in the treatment of CSV, prevention of relapses and better control of the grumbling manifestations of the disease are still a challenge under the biomedical regime (Baldini et al., 2010).

As I write this chapter, I have no known manifestations of CSV, my asthma, allergies and skin rashes are well under control and I have stopped taking regular medications 2.5 years following my early stage three diagnosis.

In undertaking this very personal doctoral research project, my aim was to be transparent and work towards being reflexive. My interest from the very beginning was to generate implications for care of chronic conditions more generally through exploring other people's experiences. Below is an extract from my second positionality interview undertaken in August 2014, following my formal admission to the doctoral programme and prior to any data collection or analysis taking place. In this extract, I answer the interviewer's question regarding what made me undertake this project:

I found the whole person [therapeutic approach] really interesting, and as I understood it going through my own therapeutic process, I started asking, well why don't people know about it? It is not hard, it is not difficult, and it makes a huge difference for patients to be treated in this way and, you know, it is being taught and yet we don't know about it... My interest [in doing this PhD] never changed. The interest was always about getting the perspective of the people who are treated. What is happening for people with chronic illness who are treated from a whole person perspective? That was always the interest... I think that the essence of this approach which is very therapeutic and helpful can be practised by people without that psychotherapeutically flavoured training. I actually think it can become much wider. (August, 2015)

At this point, I want to emphasise the most important aspects of my experience as I saw them prior to engaging with other people's experiences. First, I believed that, initially, I was only ready for a biomedical treatment to deal with the life-threatening aspects of the

CSV. This did result in me being free from CSV symptoms even though the unexplained bleeding continued. This perspective came through in my second positionality interview: *“I think that the timing, and that was in the first interview I did as well. I think that the timing of introducing this approach to patients is really important and I want to see if that also comes through”* (August, 2015). Fortunately, WPTA practitioners integrate and incorporate biomedical treatments like chemotherapy in their treatment of illnesses like CSV (Broom, personal communication August 20, 2014). I believe that the biomedical treatment was a necessary part of my disease treatment, but it was the WPTA experience in the context of the biomedical treatment that enabled me to regain an even fuller and more meaningful life, free of symptoms and the need for any medications.

Second, I firmly believed that had I only gone down the biomedical route, there is every likelihood I would still be on medication, suffering from the considerable side effects and ongoing niggling manifestations of the illness, as described elsewhere (Baldini et al., 2010; Solans et al., 2001). I am also in no doubt that I would be living a very limited life due to the ongoing impact of severe anxiety. It is well established that the maintenance of remission is a challenge with CSV patients with a considerable relapse rate during the disease course (Baldini et al., 2010).

Third, I believed it was my readiness to enter this particular type of therapeutic relationship, one that focuses on the connection between mind and body, which was key to my own healing (Broom & Joyce, 2013). Therefore, I believed that this readiness is a crucial aspect of a successful WPTA journey. To illustrate: the notion of thinking of my CSV as connected to mind aspects was first raised with me during one of my chemo sessions by one of my admitting physicians. At the time, I was extremely resistant to it. I described that encounter in my first assumptions interview:

When [the physician] tried to talk to me about WPTA, I DID NOT want to talk about it. I was like, just GO AWAY. All I needed to do was just get through this. I’ve got what I need, I can’t think about... and I talked to [my WPTA therapist] about it, that I couldn’t. And that’s the other thing; it’s the patient perspective that I am really interested in. And I am one of the more literate, health conscious and self-aware people that you might come across because of my background. And I couldn’t [do WPTA] and I actually felt quite resentful of [the physician] for raising it. At the time it was just like you transgress so many boundaries... I

am sitting here with this [chemo tube] in my arm... you don't know what it's like.
(May, 2014)

1.3 My assumptions about the WPTA at the outset of this doctoral research based on my own experience

I share the view of Clancy (Clancy, 2013) that reflexivity is a core component in how non-positivist research should be conducted and that researchers are not data-collecting machines. Being reflexive allows researchers to understand their own impact on the research so it can be explicitly acknowledged. My intent at the outset of this research was to become a reflexive researcher, able to create space in interviews and subsequent analysis. I aimed for this space to enable the richness and diversity of other patients' accounts to be articulated. My purpose was to analyse these accounts, and to create new meaning and understanding of the WPTA therapeutic process, following examples such as Underwood et al. (2010) and Wainwright (2011).

To achieve a reflexive approach throughout the process, I engaged in a number of activities and strategies to articulate my own bias at the outset so it could be explicitly acknowledged and worked with. These included the two positionality interviews referred to earlier in this chapter, which were carried out prior to commencing data collection and analysis. The first interview took place before commencing the doctoral journey in May 2014 and the second a year later, after being formally admitted to the programme. In addition, throughout the data collection and analysis process, I used continuous memoing which included documenting my positionality. These practices are described in detail in Chapter 5.

Drawing on my personal reflections above, I outline here what I thought, before undertaking this doctoral research. These were my thoughts regarding the "black-box" mechanisms that facilitated my own strong and sustainable recovery through the WPTA therapeutic process. I viewed them as falling into three distinct categories. First, there was understanding and internalising how my story was interlinked with my own illness. Second, I was ready to enter the relationship. Third, the quality of the therapeutic relationship my clinician established between us enabled the success of this approach.

1.3.1 Story and illness – Meaning-full illness

The most powerful aspect of the WPTA experience for me was coming to understand that my own biographical story was inextricably connected to my illness. Once I understood that, so many things about my life made sense. I experienced WPTA in its

very essence as a crucial process of integration of my “personhood”, where I was able to articulate the “unutterable” in a safe environment that saw me as a whole. I came to see my illness as “meaningful” in the context of my life (Broom, 2007). It is not a meaning that I, or the WPTA practitioner, imposed on the illness in retrospect; it was there all along, from the very beginning (Broom et al., 2012).

Let me take a moment to examine this concept of “meaning” in the context of my own WPTA therapeutic process. I have come to understand that my illness was meaningful and emerged within the context of my life’s story, my own history, cultural context and even spirituality, as well as my genetic makeup and environmental exposures. I learnt to not ask if it was 20% genetic and 80% everything else, or vice versa, because the journey to recovery meant I had to work on all fronts; that continuing to compartmentalise would not get me “there”.

Another powerful aspect of seeing my illness as meaning-full (Broom, 2007) was that through working with my WPTA practitioner, I also learnt to reflect on somatic meanings in language. He gently guided me to start to reflect on how the metaphors we use to describe how we feel are so grounded in our body. I found it very powerful to realise how the “blood boiling” metaphor I used to describe my anger towards certain key people in my life was very meaningful for me in the context of an in-the-blood vasculitic illness. Being bilingual in two very different languages with different syntax and alphabet (English and Hebrew), I was also able to further reflect that many of the metaphors are very similar in both languages, especially the “blood boiling” one, for which the Hebrew equivalent is about people being in “your veins” when they really get to you.

From a very practical and pragmatic perspective, this process led me to achieve greater and deeper self-awareness of how I experienced my body. It helped me regain a sense of agency with respect to my own health. I now had the ability to “listen” to my body and be aware of where “it was at”. I found that this was a very powerful way to manage anxiety over any physical symptoms because, through this awareness, I learnt to successfully differentiate between symptoms that were linked to my illness and those which related to other aspects of my life. Here’s an illustrative example from my first positionality interview:

I don’t have anxiety, when things happen in my body I am able to sit with it and articulate for myself, why have I got this sore stomach? Why are my heels

burning? [I was hospitalised for a burning sensation in my heels because of nerve damage from the CSV.] *Rather than, “Oh my god the Churg-Strauss is back.” I will sit there and ponder what is my body telling me in any given point in time.* (May, 2014)

Finally, through explicitly confronting my own unarticulated assumptions about the prevailing dualisms in how we see our world (Damasio, 2001), I became more integrative in my approach to life. The process led me to confront those embedded assumptions about the separateness of mind and body and of personal dualisms I used to live by.

1.3.2 Readiness

As outlined earlier, drawing on my own experience, I proposed at the outset of my research that the readiness of the patient to enter this specific therapeutic relationship is crucial to the success of the WPTA process. As a patient researcher with a background in psychology, I proposed that this readiness would go beyond the readiness for change that underpins the success of other types of psychological interventions (Peterson, 2009).

The WPTA process is a difficult one from a patient perspective as it requires many psychological and physical resources (Broom & Joyce, 2013) at a time when one is coping with the reality of living with a chronic illness. The day-to-day reality of patients with chronic illness can be extremely challenging, where sometimes even doing the smallest of tasks is daunting (Öhman, Söderberg, & Lundman, 2003). Personally, I did not have those resources while I was undergoing the intensive biomedical treatment. My own horizon was limited to simply functioning. I could not engage in anything else. Therefore, I started this research with an assumption that patients' readiness is a necessary ingredient in successful WPTA treatment, and I would go so far as to state that I believe there could be adverse health outcomes for patients if they are “pushed” to enter that relationship before they are ready.

1.3.3 Quality of the therapeutic relationship

The importance of quality in therapeutic relationships is well established, even though it is a complex topic with different meaning to different audiences (Ridd, Shaw, Lewis, & Salisbury, 2009). Based on my own experience, it was my assertion that the quality of this relationship in the WPTA process is absolutely essential and that the essence of this quality, which is possibly *central* to WPTA, is the ability of the practitioner to create a

“safe” environment for the patient to bring their “whole” self safely into the relationship.

Once those assumptions were explicitly documented, I intended to transparently and explicitly incorporate them into the analysis as sensitising concepts (Charmaz, 2006). These assumptions were accordingly used in constructing complex questions to ask of the data during the analytical process. For a detailed description of this process, refer to Chapter 5.

1.4 Research aims

The primary objective of this research is to describe and interpret the experience of people who suffer from chronic conditions and were treated by WPTA clinicians, in order to inform the clinical care approach for chronic conditions more broadly. It is proposed that describing and interpreting the perspectives of these people could further inform the practical application of this model, as well as providing insight for all medical professionals who work with patients with chronic conditions, such as doctors, nurses, psychologists, physiotherapists and nutritionists.

1.4.1 Defining key terms

Certain terms are used repeatedly throughout the thesis and defined here: Patient/person who is experiencing symptoms, WPTA, WPTA hospital clinicians, WPTA physiotherapists, “physical symptoms”, “diagnosable symptoms/illness”, “undiagnosable symptoms/illness”.

1.4.1.1 Terms used to describe the person receiving the treatment

I use the terminology of “patient”, “person” and “participant” throughout the thesis to reflect the context of the paragraph. When appropriate, such as when the person is seen by themselves or their treating clinicians as a “patient”, I deliberately use that term. When I comment on what a participant says in the context of reporting on their experiences, I use “participant”. I use “person” deliberately on those occasions when I want to emphasise the personhood of the “participant” or “patient”.

1.4.1.2 Chronic conditions/illness/disease

I alternate the use of chronic illness, chronic disease and chronic conditions throughout the thesis to reflect how these terms are used interchangeably in the literature reviewed, as well as by participants in this study.

1.4.1.3 WPTA

Whole Person Therapeutic Approach is a multi-disciplinary therapeutic approach that is described in detail in Chapter 2, Section 2.3.

1.4.1.4 WPTA hospital clinicians

This terminology refers to the three clinicians who have been formally trained in the WPTA, by undertaking a postgraduate course, and who work in the immunology department of an urban tertiary hospital. Two were medical doctors and one was a dietician.

1.4.1.5 WPTA physiotherapists

This refers to physiotherapists who have been formally trained in the WPTA in a postgraduate university course and who operate in physiotherapy clinics.

1.4.1.6 Physical symptoms

The WPTA is a non-dualistic approach, which does not separate mind, relational and story elements, and body-physical symptoms from participation in the illness. However, I chose to refer to “physical symptoms” or symptoms “in the body” and “mind symptoms” to delineate the reasons why people were referred to the settings researched in this thesis. “Mind symptoms” include, for example, depression and anxiety, while “physical symptoms” include pain, asthma, hives and eczema (to name but a few of the conditions participants were treated for).

1.4.1.7 Diagnosable and undiagnosable symptoms/illness or unexplained symptoms

The WPTA does not differentiate between diagnosable symptoms with a clear aetiology (like CSV) and undiagnosable or “unexplained” symptoms and illness. Nonetheless, the mainstream health system in which it operates does. Therefore, I chose to specifically refer to these, when appropriate, for the purpose of orientating the reader in this context.

1.5 Structure of the thesis

The structure of the thesis is illustrated in Figure 1. Within this chapter, I have provided an overview of the research topic, and the personal reasons that led me to undertake it. This study originated from a desire to help influence the kinds of care clinicians provide to people who suffer from chronic conditions. It is designed to elucidate the experiences of patients for the purpose of influencing how clinicians interact, work and build relationships with their patients as whole persons.

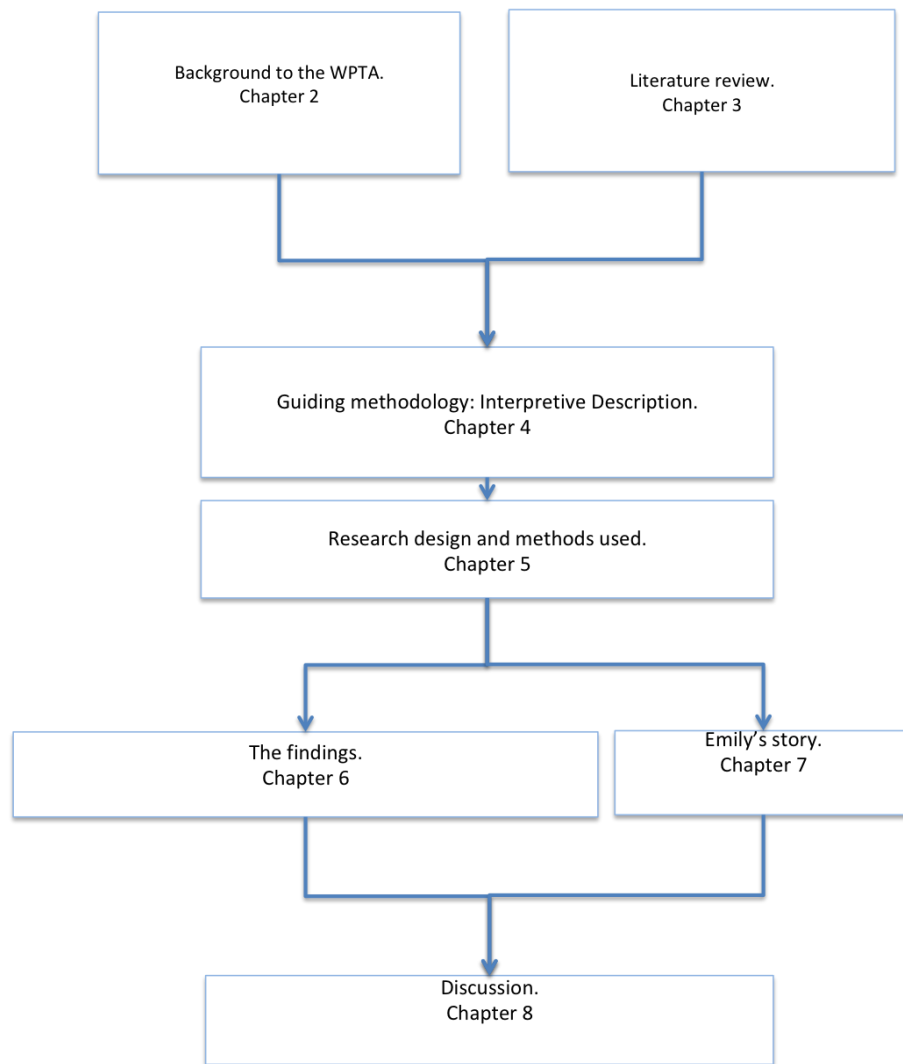


Figure 1. Thesis structure.

Chapter 2 aims to provide a critical reflection on the theoretical, conceptual and contextual influences relevant to the current research. It discusses the forces shaping contemporary approaches to healthcare and their implications for the care experience of people who are seeking treatment for chronic conditions. In this chapter, I consider the impact of mind-body dualism on mainstream, disease-focused approaches to clinical care, as well as its impact on the type of scientific evidence valued within this paradigm. I then outline the key contemporary approaches for addressing the care experiences that result and conclude by introducing the WPTA.

Chapter 3 presents a literature review drawing on principles of systematic review with regard to searching for and identifying relevant research evidence. The primary aim was to explore what is known, and not known, about the care experience(s) of people with chronic conditions in mainstream care settings. Given the focus on “experience”, it is specifically concerned with contemporary qualitative research. In this review, I

specifically consider if clinicians' views of illness aetiology appear to impact on the experience of the person being treated. Chapter 3 concludes with a methodological critique of the studies reviewed, which served to inform the design of the current study.

Chapter 4 outlines the methodological considerations which resulted in selecting Interpretive Description as the guiding methodology for this research. It includes explicitly locating the theoretical fore-structure for this study as well as my disciplinary orientation and personal relationship to this topic. The research design and methods are detailed in Chapter 5, which is structured sequentially around the five steps undertaken in conducting this research: 1. Preliminary work; 2. Secondary data analysis; 3. Primary study; 4. Analytic process; and 5. Constructing the findings vignette. Each step is outlined in detail.

The findings are reported and outlined in Chapter 6. This chapter is structured around the four overarching themes constructed in this research: seeing patients as persons and explicitly acknowledging their unique illness history, clinicians bringing their whole selves into the therapeutic encounter, negotiating first encounters, and a door into understanding. A vignette constructed for the purpose of orienting the reader towards the key findings as a whole is provided in Chapter 7. This vignette is presented as a retelling of an interview, using verbatim quotes from the primary interviews undertaken.

Finally, in Chapter 8, the discussion, I draw the different components of the thesis together with a focus on the overarching objective of this work: To provide an in-depth consideration of the experiences of persons treated in the WPTA for their chronic conditions and identifying what might be learned from these experiences that could be of general relevance to improving the care approaches to chronic conditions. I consider how the findings challenge and/or advance existing knowledge of the care experiences of people with chronic conditions generally, and specifically as they pertain to the WPTA. In this chapter, I also consider the limitations and strengths of this doctoral study and discuss implications regarding clinical practice and clinical education which arise from this research. I close by offering considerations as to future research that may advance knowledge of how incorporating and addressing the mind-body connection in mainstream care for people with chronic conditions could impact on their wellbeing and overall progress to health.

Chapter 2: Background to the WPTA

I must describe to you first the body by itself... I assume the body is nothing else than a statue or machine.

Rene Descartes (cited in Hewa & Hetherington, 1995, p. 133)

The purpose of this chapter is to provide the theoretical underpinning and context for the current research. It attempts to deal with the forces shaping contemporary approaches to healthcare and their implications for the care experiences of people seeking treatment for chronic conditions.

In this chapter, I mainly use the term “patient” to describe the person receiving care because of the overwhelming use of this term in the literature reviewed. The use of this term reflects an important aspect of the literature reviewed, much of it written by clinicians, in that the person receiving the care is still first and foremost seen as a patient.

This chapter is in three parts. In Part 1, I set the scene for the contemporary biomedical approach that is dominant in “mainstream” health settings. I do this by first providing a brief historical context for the prevailing mind-body dualistic view of health and illness and its associated disease-focused model of care. I expand on this by providing an overview of a key prevailing paradigm in modern healthcare, “evidence-based medicine” (EBM), and the hierarchy of evidence underpinning it. The section ends with an outline of critiques levelled at the impact that adherence to this paradigm has had on the patient experience.

Part 2 of this review is concerned with contemporary attempts to address limitations of modern medicine when it comes to the patient experience: the movement towards person-centred healthcare provision. I do this first by outlining its proposed origin in the biopsychosocial model, and then elaborate on contemporary writings in this field. I then return to the question of mind-body separation and examine the extent to which dualistic conceptualisations of health and illness are addressed within person-centred healthcare.

In Part 3, the question of mind and body connectivity in the context of chronic physical symptoms and illness is addressed. I do so by introducing the approach researched in this doctoral research: the WPTA. This model informs the central question of this doctoral research, which is:

What can be learned from an in-depth consideration of the experiences of persons treated in the WPTA for their chronic conditions that could be of general relevance to improving the mainstream care approach to chronic conditions?

2.1 Part 1: Scene setting

2.1.1 Mind-body dualism and the “disease-focused” biomedical approach to healthcare

Historically, the Ancient Greeks viewed illness from a “holistic” perspective. In that context, holism reflected the idea that body and mind were inseparably connected and that the whole person should be taken into account/understood in order to understand illness and disease (Halpert & Drossman, 2005). It has been suggested that the major shift occurred in Europe through the influence of Rene Descartes who proposed ontological dualism—the separation of the mechanical and material “rule-bound” body from the spiritual soul responsible for emotions and thoughts (Borrell-Carrió, Suchman, & Epstein, 2004) or, to put it a different way, the thinking, wilful mind (Jayasinghe, 2012).

Some suggest that Descartes’ vision was that the body and soul do in fact interact. However, the development of the Cartesian worldview in the 19th and 20th centuries led to the contemporary prevailing conceptualisation that the body was more real than the mind (Borrell-Carrió et al., 2004). Cartesian dualism still underpins much of how Western medicine views illness and disease by privileging the observable. This has been argued as impacting on patients’ experience, in that those who suffer from a physical illness, with symptoms that can be objectively observed or measured, are prioritised over those whose symptoms cannot be objectively observed (Anjum, 2016; Borrell-Carrió et al., 2004; Crowley-Matoka, Saha, Dobscha, & Burgess, 2009; Damasio, 2001). Indeed, many have argued that because of the influence of Cartesian dualism on the prevailing biomedical paradigm, mental and physical domains of healthcare are not just separated in how they are taught or treated, but are prioritised differently (De Camargo & Coeli, 2006; Johnson, 2013).

The biomedical model, it has been argued, is based on the following premises:

- A mechanistic view of the body as separate to the mind, and that the body is essentially a material entity (Engel, 1977). As a consequence, diseases are seen as primarily physical in nature and are located in a specific organ/s or system (Crowley-Matoka et al., 2009; Hewa & Hetherington, 1995).

- Building on the above, and in keeping with reductionist principles, any given disease with physical symptoms should have a narrow, biological mechanistic aetiology. This results in the clinical assumption that, in order to cure an illness, the aetiology needs to be objectively observed, identified and modified (Crowley-Matoka et al., 2009; Engel, 1977). This is seen as both necessary and sufficient for explaining the illness and therefore curing it (Jayasinghe, 2012).
- Illnesses have been historically classified by physicians into two distinct groups: “organic” or “functional”. Organic illnesses are the province of the medical professions. These are diseases/illnesses/disorders with objectively observable pathophysiology. Functional disorders are those with no objective or measurable pathophysiology, poorly defined or difficult to understand symptoms, and an unclear aetiology. As a consequence, functional illnesses/conditions have no systematic path for treatment and tend to be regarded as psychological (Werner, Isaksen, & Malterud, 2004).

The implication for medical practice is a widespread assumption in mainstream Western healthcare that diseases which have measurable, physical manifestations can be therapeutically addressed without consideration of mind factors (Broom et al., 2012). However, there have been growing concerns and criticisms that the biomedical scientific model’s focus on disease tends to constrain, and at times avoid altogether, consideration of a wide range of social, psychological and environmental aspects of illness and suffering (De Camargo & Coeli, 2006; Hewa & Hetherington, 1995). There are also concerns that the reality of the person who is sick is lost when the medical professional assumes a tunnel vision focusing on those physical symptoms that fit the prevailing biomedical disease model (Crowley-Matoka et al., 2009).

Consequently, modern medical education and practice in the Western world is now typified by a scientifically based, reductionist and technical application of procedures and administration of drugs (De Camargo & Coeli, 2006; Miles, 2009a). This may be seen to correspond with reports of patients’ experiences of feeling reduced and objectified (Gergel, 2012). Indeed, in a book based on many interviews with people suffering from chronic illness, Royer (1998) describes how a former family physician, himself diagnosed with a chronic illness, discovered that upon diagnosis he too was “treated as a moron” (p. 29). Royer (1998) comments: “Thus besides a decrease in quality of life, one of the consequences of chronic illness seems to be the frustration chronically ill people feel in their interactions with health care professionals” (p. 29).

The dualistic biomedical approach, it has been suggested, particularly impacts on the experiences of patients with complex circumstances, and hard-to-diagnose conditions. There are many descriptions of how clinicians view such patients as complex to deal with, as nuisances about whom they have even, in some cases, devised derogatory nicknames to describe. Terms such as “heart-sink” (Tarrant, Windridge, Baker, Freeman, & Boulton, 2015), “GOMER” (Get Out of My Emergency Room) and “crock” have been reported (Hewa & Hetherington, 1995; Spencer & Grace, 2016). This denigration of “complex” patients was echoed in a Brazilian study observing the practice of medical residents where women were described as being “pitizentas”, an untranslatable and somewhat derogatory term used by Brazilian doctors to describe patients with complaints which do not seem to have an observable biological basis (De Camargo & Coeli, 2006).

Furthermore, the literature suggests that people with unexplained symptoms, such as fibromyalgia, are patients that some physicians try and avoid, and characterise them as “difficult” and as having psychosomatic symptoms and psychological disturbance (Wolfe & Walitt, 2013). This focus on psychological disturbance possibly represents a contemporary move to use more socially acceptable terms, but may represent an equally derogatory attitude towards some persons with “difficult to diagnose” chronic conditions.

Some commentators argue that the disease-focused approach has resulted in doctors who “view the person of the patient as an irritating distraction between themselves and the disease they are attempting to treat” (Miles, 2009a, p. 945). Therefore, persons who are sick may be left wondering if medical professionals forgot that, although “science can cure illness, science can’t care for patients” (Miles, 2009a, p. 943). This observation is reflected in the shared experiences of many people who suffer from a chronic illness; see, for example, the work of Tania Gergel (2012, 2013).

This dualistic, disease-focused approach, where a clear aetiology is to be objectively identified for treatment to occur, is the foundation on which many of the current approaches to educating clinicians and delivering healthcare have been built (Broom, 2016b). In particular, a prevailing force influencing much of the health-related experiences of the modern patient is EBM and its associated treatment protocols (Charles, Gafni, & Freeman, 2011).

2.1.2 Evidence-based medicine and hierarchy of evidence

EBM, as the paradigm underpinning the protocol-driven practice of medicine, was developed in the 1990s, in response to what was seen as over-reliance on expert opinion in medical diagnosis and treatment (Greenhalgh, Snow, Ryan, Rees, & Salisbury, 2015). This was viewed as overly subjective and therefore too vulnerable to human error. In this context, EBM has been defined as the “application of methods of clinical epidemiology to the practice of medicine more generally” (Solomon, 2011, p. 452). Sackett wrote, “Evidence based medicine is the conscientious, judicious and explicit use of current best evidence in making decisions about the care of individual patients” (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71).

The original aim of EBM was to encourage the development of scientific methods that would result in clinically applicable and unbiased data for the purpose of overcoming the limitation of the subjective, expert clinical judgement (Boyd & Kent, 2014). Central to the EBM epidemiological approach is the concept of the “hierarchy of evidence” and at the epicentre of the EBM paradigm is the rigorously designed “randomised controlled trial” (RCT) (Sandelowski, 2004; Solomon, 2011). RCTs are seen as the primary source of evidence for effective treatment protocols for a particular condition (van Baalen & Boon, 2014).

Davidoff, Haynes, Sackett, and Smith (1995) proposed that EBM is rooted in the following premises:

1. The best available scientific evidence should be the basis of clinical decisions.
2. The focus should be on the clinical problem, not habits or protocols, and it is the clinical problem that should determine the type of evidence sought.
3. In order to identify the best evidence, epidemiological and biostatistical ways of thinking are required.
4. The conclusions achieved from the identification and critical appraisals of evidence are only deemed useful if put into actions in patient management or healthcare decision-making.
5. Medical performance should be constantly evaluated.

EBM has many merits, especially in successfully treating diseases, in many cases, vis-à-vis pharmacology advancements. However, as a contemporary and pervasive force in

the modern approach to healthcare, EBM has had its fair share of criticism (Greenhalgh et al., 2015; Miles et al., 2000; Seshia, Makhinson, Phillips, & Young, 2014). The critiques most relevant for this research are those concerned with the impact of EBM-based practices on patient experience.

The impact of EBM on the *practice* of medicine has been critiqued extensively, see for example Seshia, Makhinson, Phillips, et al., (2014) and Seshia, Makhinson, and Young (2014). When it comes to influencing how patients are treated, EBM, according to Greenhalgh (2013), rests on three underlying assumptions. First, that clinical practice is more or less the same as clinical decisions. Secondly, that mathematical prediction is the best evidence for clinical decisions. Lastly, that mathematical evidence from population studies can be mapped to decisions for individual patients (Greenhalgh, 2013).

With its focus on population studies, EBM produces population-based generalisations which are then applied to an individual patient (Greenhalgh, 2013). Therefore, the underlying assumption is that what is statistically “right” for a population, is also the correct approach for the person in front of the clinician. However, trials are necessarily undertaken without attending to the singularity of that person and their experiences, history, social networks, and personality, to name but a few factors that may influence how an individual may respond to actual treatment (Greenhalgh et al., 2015).

The dominance of quantitative or biostatistical approaches that are inherent to trials may also impact on how individual patients are considered and treated. That is, by privileging the RCT as “best evidence”, associated data methodologies are privileged in clinical decision-making. RCTs, by their very nature, are solely focused on things that clinicians can see and measure. It is suggested that this emphasis on “if we cannot measure it, it doesn’t exist”, has resulted, probably unintentionally, in amplifying the disease-centred clinical decision-making modus operandi (Greenhalgh, 2013). By this I refer to an assumption, revealed in practice, that what is right for the disease (based on EBM protocols) is seen as automatically right for the patient (Boyd & Kent, 2014). This may have contributed to the increasingly depersonalised experiential nature of modern medicine where the clinical and institutional “gaze” has moved away from the patient as a person (Miles, 2009a) towards a practice that focuses more on the technical application of “evidence-based” guidelines (Charles et al., 2011; Miles & Loughlin, 2006, 2011).

Furthermore, RCTs, more often than not, are carried out with homogeneous, uncomplicated and complying patients, in circumstances (and a context) where confounding variables are strictly controlled and accounted for (Kersten, Ellis-Hill, McPherson, & Harrington, 2010). In the real world, “confounding variables” are abundant and people with chronic conditions quite often have more than one chronic condition they are living with (De Leon, 2012; Hampton, 2002). It has been argued that applying protocols derived from such studies to the day-to-day care of the individual who is ill represents a crucial misunderstanding between the partial and specific nature of the disease and the wholeness of the person carrying the illness/disease (Miles, 2009a).

The critique outlined in the previous two sections is not new. Concerns regarding the impact of the dualistic, reductionist approach of contemporary biomedicine, which some argue is exacerbated by the prevailing reliance on EBM protocols, and its impact on the experience of patients, have been voiced for over 20 years (Bensing, 2000; Hewa & Hetherington, 1995). Indeed, there is a very large body of scholarly work specifically concerned with finding ways to address some of the issues outlined previously, by focusing on improving the experience of patients, especially those with chronic conditions (Miles & Asbridge, 2016). Part 2 of this review is concerned with the contemporary movement attempting to address the limitations outlined; the movement towards person-centred healthcare provision. I do this first by outlining its proposed origin in the biopsychosocial model, and then elaborate on contemporary writings in this field. I then return to the question of mind-body dualism and attempt to examine the extent to which dualistic conceptualisations of health and illness are addressed under the biopsychosocial model.

2.2 Part 2: Efforts to humanise the system and move towards person-centredness

Patient-, or person-, or client-centredness are global approaches to addressing the increasing dissatisfaction with the reductionist focus on illness/conditions/symptoms in contemporary healthcare (Leplege et al., 2007). The different terms used are indicative of the multidimensional nature of this concept. This movement has been linked to a number of humanistic traditions including that of the American psychologist Carl Rogers (Leplege et al., 2007). The biopsychosocial model of healthcare, a term first coined by Engel, has also been linked to this global shift in discourse around healthcare provision (Biderman, Yeheskel, & Herman, 2005; Halpert & Drossman, 2005). In this

section, I provide a brief overview of the biopsychosocial model in order to contextualise this movement in discourse. In the section below, I have deliberately alternated between the use of “patient”, “person”, and “client” to represent the varied language used in this field as it grapples with defining what centring healthcare delivery away from “the system”, “the illness” and “the clinician” actually means (Miles & Asbridge, 2016).

2.2.1 The biopsychosocial model

An overemphasis on disease, while neglecting the person suffering from the disease, has been debated and highlighted for at least the past 40 years (Biderman et al., 2005). One of the most well known responses has been the biopsychosocial model. First outlined by Engel (1977), the biopsychosocial model does not abandon the biomedical model; rather, it extends it by approaching all ill health and disability as incorporating feelings, thoughts, behaviour, the social context of the person, and the way they all interact with both the physiology and pathophysiology of the condition (White, 2005). It offers a modern interpretation of holistic theory (Borrell-Carrió et al., 2004), in that it proposes that illness and disease result from the simultaneous and multi-level interaction of biological, psychological and social sub-systems. It also proposes that those cannot be separated because they also explain the person’s experience of the illness (Adler, 2009; Engel, 1977). Leplege, Barral, and McPherson (2015) suggested that Engel never intended to propose a model, nor focus on the system; rather, that his efforts were aimed at improving medical education for individual patients’ benefit. Regardless, it has gained widespread recognition as a model.

Philosophically, the biopsychosocial model is a way of understanding how suffering, disease and illness are affected by multiple levels of organisation, from the societal to the molecular. At the practical level, it is a way of understanding the patient’s subjective experience as an essential contributor to accurate diagnosis, health outcomes and humane care (Biderman et al., 2005). The implications as to the preferred mode of evidence under the biopsychosocial model were that “clinical” research was favoured over “biological”, symptom-focused research. Therefore, the biopsychosocial model was seen to advocate interdisciplinary work, which attends to all aspects of the person, and thus promotes “wholeness” (White, 2005).

However, careful reading of Engel’s (1977) seminal work reveals that Engel is critiquing the power imbalance between patients and physicians, as well as the professional hierarchy within the medical profession, which he argues has emerged

from the dogma of biomedicine. Engel (1977) also thoroughly illustrates how the social system of the biomedical hospital perpetuates those power imbalances and hierarchies. He highlights how the dogma of biomedicine results in physicians who tend to use scientific evidence as the basis for decision-making, because they are rewarded for it professionally, and do not prioritise the therapeutic value of the patient-doctor relationship. This is demonstrated by the following extract:

It [the biomedical model] encourages bypassing the patient's verbal account by placing greater reliance on technical procedures and laboratory measurements. In actuality the task is appreciably more complex.... An examination of the correlation between clinical and laboratory data requires not only reliable methods of clinical data collection, specifically high-level interviewing skills, but also basic understanding of the psychological, social and cultural determinants of how patients communicate symptoms of disease (Engel, 1977, p. 131)

It has been suggested that what was most innovative about Engel's model was that the concept of "social" shifted away from the immediate, personal and social context of the patient to the role of the healthcare system in propagating and relieving illness (White, 2005). Writers such as Johnson (2013) describe the central contribution of the biopsychosocial model was to the growing interest and development of different modes of healthcare delivery, such as patient-centred practice and multi-disciplinary teams for the treatment of disease, especially chronic disease.

However, despite their work underpinning significant advances in how illness was viewed and treated, Engel (1977) and others did not attempt to address the issue of disease aetiology in the context of the individual person. That is, the separation of mind and body in explaining illness aetiology is left unchallenged. Illness with clearly defined observable aetiology is still seen as "biological" and illness without such a clear aetiology is seen as "psychosomatic". In stating that:

One of the more lasting contributions of both Freud and Meyer has been to provide frames of reference whereby psychological processes could be included in the concept of disease. Psychosomatic medicine – the term itself a vestige of dualism – became the medium whereby the gap between the two parallel but independent ideologies of medicine, the biological and the psychosocial was to be bridged (Engel, 1977, p. 134)

It remains somewhat unclear whether Engel in fact remains dualistic as to the aetiology of illness. Despite over 3,000 journal articles in peer reviewed publications citing Engel's model (as of March 2015 on Scopus), it would seem, and others such as White (2005) have argued, that the experience of being treated in the medical system has become even more disease-centric (as opposed to patient- or person-centred) since the 1970s. Writers have attributed this to a range of forces within the medical system, from the success of pharmacology in treating a wide range of illnesses (White, 2005, and as outlined in the previous section), to the prioritisation of evidence derived from clinical trials and epidemiological studies over all other types of evidence, including clinical and expert based opinions.

Nonetheless, it has been argued that the contemporary and influential development of the person-centred care movement has been influenced in part by the biopsychosocial model (Bensing, 2000; Leplege et al., 2007; Miles, 2009a; Thorne, Ternulf Nyhlin, & Paterson, 2000). In the following section, I attempt to provide a brief overview of what is meant by person-centred care, how it has been conceptualised, implemented and researched. I specifically attend to the research done concerning the patients' experience and the degree to which it addresses the underlying assumption regarding mind-body dualism.

2.2.2 What is person-centred care?

There have been many, quite different conceptualisations of person-centred care, with some arguing the concept is still up for grabs (Marcum, 2015). Indeed, some articulations have been centred around transforming the therapeutic relationship into a more mutual model of care, seeking to tailor care to patient's needs and respectful of the person's expertise. For example, under some conceptualisations of this model, it is hoped that physicians inform their clients much more than they used to, address personal wishes, discuss therapeutic options and their impact on the person's life, and seek agreement and informed consent before taking action, thus respecting the person's competence (Leplege et al., 2007). This particular conceptualisation of person-centredness may be seen to advocate better ways to have conversations that enable shared decision-making, based on quality information sharing (Richards, Coulter, & Wicks, 2015).

As a concept, person-centred care can be viewed as one approach to practice that supports the operationalisation of the biopsychosocial model in practice, given its orientation towards the person, and not the disease (Biderman et al., 2005; Halpert &

Drossman, 2005). Person-centredness has been contrasted with “disease-centred”, “hospital-centred”, “technology-centred” and “doctor-centred” healthcare (Baathe, Ahlborg, Edgren, Lagstrom, & Nilsson, 2016). In contrast to these approaches, a core assumption of person-centredness is that the patient is always more than his or her illness, and that not all care decisions should be solely based on what is “best for the disease” (Bensing, 2000). In essence, person-centredness could represent a shift from clinicians asking, “What is the matter with you” to “What matters to you?” (Baathe et al., 2016).

This focus on joint decision-making and communication is indeed echoed in guidelines for practice by organisations such as the UK Health Foundation. The foundation asserts that person-centred care is underpinned by three principles of care which are personalised, coordinated, and enabling. Further, they suggest that for care to be enabling, “the relationship between health care professionals and patients needs to be a partnership rather than the professional being the expert while the patient simply follows their instructions. It is a relationship in which health care professionals and patients work together” (The UK Health Foundation, 2014, p. 8).

However, these patient-led approaches may hinder a deeper appreciation and understanding of what person-centred care could become, because of their focus on, and prioritisation of, economic and political considerations (Dahlberg, Todres, & Galvin, 2009). Dahlberg et al. (2009) argue against some of these conceptualisations of person-centred care as being derived from consumer- and citizen-driven models of service delivery, and do not consider the essence of what it is to be human. Dahlberg et al. (2009) offer an alternative interpretation of patient-led care that they named “lifeworld-led care”, which is concerned with the essence of being human and accommodates notions of both a person’s agency and vulnerability.

The various conceptualisations of person-centred care have contributed to a strong emphasis on the quality of relationships between the person who is sick and their care providers. A framework of relationship-centred care, where relationships are explicitly acknowledged for their significant influence on healthcare experiences and outcomes, has even been proposed as an alternative to person-centred care (Soklaridis, Ravitz, Adler-Nevo, & Lieff, 2016). Therefore, the clinical importance of clinicians developing their humanistic skills as a way of facilitating good relationships which are seen as necessary for recovery and health have been advocated (Mark & Lyons, 2010). Skills such as compassionate listening are emphasised (Biderman et al., 2005), as well as

advocating for clinicians to work on their self-awareness and pay careful attention to their bias (Borrell-Carrió et al., 2004).

More recently, calls have been made to move articulations of person-centredness in the context of clinical practice beyond the dyadic clinician-individual patient relationship, to include the inter-professional contexts, as well as the organisational culture (McCormack & McCance, 2016). Viewed in this way, person-centredness is not something that can be technically applied and measured using “tick the box” type guidelines. Rather, achieving person-centred practice requires a specific type of workplace culture and context to exist (Dewing & McCormack, 2016).

This has resulted in a definition of person-centredness that explicitly includes relationships between healthcare providers, as well as between providers and service users and those close to them. McCormack and McCance (2016) define person-centredness as:

... an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development. (p. 3)

This definition is of particular relevance for this PhD as it acknowledges how a health organisation’s culture plays a central role in making it possible for individual care providers to operate in a person-centred way.

Nonetheless, contemporary conceptualisations of health and illness may present under-acknowledged barriers for achieving person-centredness. For example, in current definitions of person-centredness, there is no explicit acknowledgment of the role of other “mind” factors in the aetiology of a physical illness. Further, where there are clearly observable mechanistic processes, it is uncommon for “mind” factors to be seen as integrally relevant to the treatment approach. Therefore, clinicians may choose to engage with the person they are treating in a more caring, “holistic” way because of their personal philosophy or values, and yet the underlying dualistic assumptions remain unchallenged. The “mind” component is seen as important, and yet is still conceptualised as secondary to the treatment of the physical symptoms (Broom, 2002, 2007).

Viewed in this way, person-centredness has not, to date, explicitly attempted to address the dualism inherent in the biomedical system as it pertains to the aetiology of illness. It is conceivable that with a “dualistic” worldview of disease aetiology, clinicians who may strive to be person-centred might still find themselves disease-focused when short of time, working in an environment which is not supportive of that orientation, and faced with a person with a clear, diagnosable, “under the microscope” biological aetiology of their physical illness.

2.3 Part 3: What about the mind-body connection?

Notwithstanding the efforts to re-orient the care approaches away from the “illness” and back to the “patient”, dualism of the mind-body separation remains the underlying assumption in most, if not all, modern, biomedical, health teaching and care institutions. Arguably, this assumption orients the biomedically trained clinician *a priori* toward the person in front of them. In the final section of this chapter, I outline the therapeutic approach which is the subject of this research: the Whole Person Therapeutic Approach (WPTA). The WPTA is built on an underlying co-emergence model, a non-dualistic conceptualisation of health and illness.

2.3.1 The Whole Person Therapeutic Approach

The WPTA is a particular approach of person-centredness which explicitly addresses dualistic assumptions. Drawing on psychotherapeutic concepts and models, it is a clinical approach which actively addresses the impact of life events and relational dynamics on the body. Because of its psychotherapeutic origin, the WPTA invites clinicians, together with their patients, to explore the patient’s histories, stories, and other life dimensions. Alongside these explorations, the WPTA embraces the advances and strengths of biomedical science. The focus is on the whole, unified person (Broom, 2016b). For example, the WPTA clinician might focus on physical symptoms and flare-ups and coincidental life experiences and life stories to access links between mind and body, because they see the patient’s physical symptoms as potentially meaningful in the context of these life dimensions (Lindsay et al., 2015). It has been reported that this unique blending of the subjective story and standard biomedical approach has resulted in unexpected improvements in patients with chronic conditions who had previously not responded to conventional biomedical treatments (Broom, 2016b; Broom et al., 2012; Lindsay et al., 2015). The WPTA explicitly addresses the impact of dualism on the experience of care in contemporary biomedical healthcare. A key assumption

underpinning the WPTA is the co-emergence model of mind and body development, which is described in the following section.

2.3.1.1 The co-emergence model of mind and body development and implications for person-centredness

The WPTA assumes that subjective and intrinsically individual “mind” elements such as psychological factors, personal history, experiences, feelings, relationships, psychosocial factors, spirituality and cultural influences, to name just a few, are potentially important factors in the development and progression of physical disease (Broom, 2016b). It assumes this can be the case whether in predisposition, precipitation or perpetuation of physical illness. Therefore, under this model, attending to these elements is potentially important in providing good treatment to persons with any disease, not only those considered to be “psychosomatic” (Broom, 2002, 2007; Broom et al., 2012).

Within the WPTA, the notion of co-emergence, as applied to illness, asserts that physicality (the reality that humans are physical beings) and subjectivity (the reality that humans are experiencing and “minded” beings) co-emerge from the beginning of life. They are never separated. They develop together and are aspects of the unified whole. Persons are born into a given environment and unique family context and from there they develop a unique and specific history. What happens to persons as individuals as they grow, develop and experience, has both “mind” and “body” dimensions (Broom, 2002, 2007).

It follows that illness, when it occurs, emerges out of a multi-dimensional state. Thus, all illness is conceptualised as an expression of persons-as-wholes, as individuals, genes, environment, eating habits, histories, thoughts and emotions, and all other aspects that make a person human. Viewed in this way, all incidents concerned with physicality ought to be considered within the context of the person. One person may experience a severe attack of an illness in one context, whereas another with the same illness may be triggered in entirely different circumstances. Because meaning is such a crucial aspect of human experience (Broom, 2002, 2007), the WPTA asserts that meaning will feature prominently in disease expression, both in aetiology and in the post-diagnosis experience. Put simply, it is assumed that the body and its mechanisms and the personal experience, meanings, and story of the person who suffers from a sickness, are interwoven (Broom et al., 2012).

In their article setting out the framework for the co-emergence concept, Broom et al. (2012) differentiated the essence of this from other models which attempt to explain the complex inter-relationship between subjective personhood and illness, such as advances in psychotherapy, narrative medicine and psychoneuroimmunology (PNI). They argue that all those models hold on to some elements of mind-body duality and that the relations between mind and body are conceived of as essentially linear—a dualistic movement or influence from one reality to another. For example, in PNI, psychosocial “stress” factors might contribute in a linear way to physical illness, from the mind/brain to the body (Jaremka, Lindgren, & Kiecolt-Glaser, 2013).

A conceptualisation of co-emerging, complex mind-body interactions may orient both the clinician and the person differently in how these dimensions are addressed. Linear cause-effect conceptualisations, in which a stress factor is seen to trigger the illness, may result in unintended, reductive consequences, in terms of how illness is perceived. These types of linear models may result in patients blaming themselves, or physicians even blaming the patient for triggering their own illness because of “too much stress”.

In co-emergence terms, illness “always already” has subjective and physical dimensions. These dimensions are most commonly accessed by WPTA clinicians through a verbal exploration of the person’s *meanings*. Drawing on psychotherapy, clinicians access these *meanings* through carefully attending to the ways persons (with a chronic condition or sickness) express themselves. Meanings, according to the co-emergence model, are potentially present in the aetiology of the specific illness. Broom et al. (2012) also suggest that when observed carefully, and understood in the context of a person’s whole life, diseases can be highly symbolic, and the ways by which the disease is expressed in the body can be “vividly congruent” with the specific life context of the individual.

Broom (2007) uses multiple case studies to illustrate diverse physical conditions with symbolic elements. For example, there is the case of an elderly woman referred for an immunological opinion concerning a widespread thickening of her skin. Broom (2007) described how when she was assessed, she spontaneously and vividly described her recent experience of responding to falling in a public space (an experience seemingly unrelated to the condition she was referred for). She used many expressions such as “going into my shell” and “shutting herself away” to describe how she conducted herself following the fall. Broom (2007) goes on to describe how the woman

spontaneously recovered when a friend insisted that she “came out of her shell”, asserting that this thickening of her skin was symbolic of a shell.

The use of such vivid case studies may risk resulting in narrowing clinicians’ focus on searching for such symbolic elements with all their patients. It may even lead to patients searching for such symbolic elements in their own illnesses. Further, when presented in such a way, it may lead the reader to believe that when the symbolic element is found, the illness will disappear. This may risk disappointment when such symbolic elements are not present, and if they are present, that they do not spontaneously resolve. An unintended and different type of dualistic thinking may occur, one which prioritises these life-dimensions and stories over the physical elements of the illness.

The co-emergence approach is, however, highly cautious in asserting that, even though this clear symbolism can be found in many cases, this may not be true for all cases. Therefore, clinicians should not always be searching for it. However, they suggest that, regardless of whether or not symbolism is present, all illness potentially entails significant, individual, subjective meanings. The implication for medical practice is “for understanding physical disease, moving clinical preoccupations from mainly body toward considering mind, body, family, culture and environment all in the same clinical time/space” (Broom et al., 2012, p. 17). Nonetheless, clinicians who are first exposed to WPTA, co-emergence, and symbolic illnesses may still risk focusing their treatment on searching for such vivid symbolism because of the emotional resonance of the case studies portrayed.

The clinician who operates from the WPTA will prescribe medication, and biomedical treatment regimes, as required. These clinicians will also attend to the meanings because of their conviction that “mind” factors with specific meaning for the individual potentially play some role, big or small, in the presented disease (Broom, 2016b). People are different, some are able to present and articulate their specific meanings and stories using their language, and others do so in how they interact with others. Others, still, may present their meaning in their bodies, and perhaps most persons do so in multiple ways (Broom, 2002, 2007; Broom et al., 2012).

This model, by its very definition, necessitates that medical practitioners attend to the person with the disease as well as the disease (Broom et al., 2012; Miles, 2009a). It requires clinicians to have the capacity to create a clinical space where persons with chronic conditions are able to convey their stories. Clinicians need to be able to

carefully attend to the meaning in the stories and engage deeply with the person in front of them (Broom & Joyce, 2013).

Dr Broom developed the WPTA within internal medicine consultations. He has also trained and worked as a psychotherapist. As a result, people referred for internal medicine consultation were assessed from both physical/physiological perspectives and psychological perspectives (Broom, 2002). According to Broom (2002, 2007), the clinical approach of combining internal medicine and a psychotherapeutic approach to physical illnesses resulted in the uncovering of “profound connections” between the person’s own understanding of their personal history and experiences, and the development of the disease/illness. This, in turn, has led to the development of a unitive model of persons, a movement away from mind and body dualism in healthcare, a concept of co-emergence of mind and body development, and the systematic use of the WPTA in treating physical symptoms and illnesses (Broom, 2007).

The theoretical underpinnings and skills of the WPTA are taught as “MindBody Healthcare” at Auckland University of Technology in New Zealand as a postgraduate diploma and a master’s degree in the Department of Psychotherapy. It is practised by health practitioners in diverse disciplines, including physicians, nurses, physiotherapists, and psychotherapists. Alongside their discipline’s therapeutic approaches, clinicians incorporate respect for the experience and context of their clients in the broadest sense. They take into clinical consideration relational factors in the person’s life, including intimate relationships, and societal and sociological factors such as poverty and marginalisation (Broom et al., 2012; Broom & Joyce, 2013).

2.3.1.2 Limitations and gaps

As described above, the WPTA is inherently and explicitly a relational practice. Because of this, similar to other relationally focused approaches, its success depends, at least in part, on the skill of the individual practitioner. With the explicit focus on the individual, their life’s story and emotional life (e.g. Broom, 2000, 2002, 2007), WPTA may be seen to privilege a particular kind of historical, biographical information. Whereas skilful WPTA clinicians may enact the various dimensions of person-centredness described in Section 2.2.2, it is possible that less skilled or less knowledgeable clinicians may be overly focused or sensitised to the biographical dimensions of the person and not incorporate other important dimensions of person-centredness in their practice.

For example, being overly focused on the relational and biographical dimensions may result in clinicians overlooking the importance of also attending to the patient's difficulties in everyday life as a consequence of the illness and the burden of the treatment (Demain et al., 2015; Ridgeway et al., 2014; Sav et al., 2013). In addition, while WPTA clinicians rely on patient's expert knowledge of self to elucidate connections between their personal narratives and illness, it is not necessarily explicit within the approach to draw on their expertise in a similar way when determining the appropriate therapeutic regime. There is a growing body of evidence which highlights the formative nature of treatment beliefs in determining the likelihood that a person will follow treatment recommendations (Horne et al., 2013). As such, seeking to understand personal treatment beliefs, concerns, values and preferences (e.g., see Dima et al. (2013), may create the context for shared decision-making—an important dimension of achieving a person-centred practice (Leplege et al., 2007; Martin & Felix-Bortolotti, 2014; Thorne et al., 2000).

Similar to critique levelled at other writings on person-centredness (McCormack & McCance, 2016), the WPTA is focused on discrete therapeutic encounters between a patient and a practitioner. As such, it does not explicitly address (and nor does it intend to) systemic, organisational, cultural issues that may inhibit the ability of clinicians to practise in particular ways. With the exception of individual WPTA clinicians' accounts of their personal journeys in trying to operate in this way within mainstream healthcare organisations (Broom & Joyce, 2013), there has been limited explicit discussion of how health services can be systemically organised and structured to enable more clinicians to work in this way. These cultural aspects may be particularly important, as organising health services to foster a culture of openness among clinicians and empowerment to continuously develop and improve their practice (McCormack & McCance, 2016), may increase the likelihood of more clinicians incorporating WPTA in their work.

Practising the WPTA within most mainstream contexts can be challenging for clinicians (Broom & Joyce, 2013). Some clinicians may further struggle to incorporate aspects of the WPTA, which draws heavily on psychotherapy, within their own clinical context (Broom, 2016b). The WPTA focus on considering all aspects of the person's subjectivity as relevant to the treatment of any given illness may be interpreted and practised differently by clinicians from different backgrounds. The over-reliance on case-history evidence, with much of the writing focused on illustrative case examples, written from the clinician's perspective, could have contributed to the observation that

the WPTA is currently taken up by only a small proportion of health professionals (Lindsay et al., 2015). I therefore propose that additional evidence is needed to support its wider adoption into mainstream healthcare. This study is a first step in contributing to the empirical evidence base through exploring the experiences of persons with chronic conditions who received WPTA care, from a diverse range of WPTA clinicians within mainstream health settings.

2.3.2 Summary

This short overview has attempted to provide the contextual and theoretical underpinning for the WPTA, which is the subject of this study. In doing so, I outlined the two dominant contemporary paradigms of the medical healthcare approach: EBM and person-centredness. I have also attempted to highlight that neither appear to challenge (nor profess to challenge) the underlying assumptions of mind-body duality apparent in the biomedical model and the implications of this for the experience of care by people who are sick. I also outlined how the WPTA, non-dualism and a co-emergence concept do offer a way of “operationalising” a clinical practice that incorporates mind elements in the treatment of all physical illness in traditional biomedical settings.

In the next chapter, I review and critique qualitative studies examining the care experiences of persons with chronic illnesses. The studies are reviewed and critiqued for the purposes of establishing what is already known about a person’s experience of being a chronic patient in a therapeutic encounter, and how these studies might elucidate the extent to which clinicians’ implicit, dualistic assumptions may affect those experiences.

Chapter 3: Literature Review

The main purpose of this review was to ground this study within the existing knowledge of what is known about experiences of the therapeutic encounter, from the perspective of persons who live with a chronic illness. Consistent with Interpretive Description (Thorne, 2008), this review provided the scaffolding for this doctoral research as it helped identify the potential issues, the types of findings and methodological challenges associated with studying the experience of the therapeutic encounter from the perspective of persons living with a chronic illness.

In this chapter, I outline the review methods and findings, and critique and comment on the strengths and weaknesses of 14 qualitative studies examining the care experiences of people with chronic illnesses. Given the research question and focus on the WPTA, in addition to examining care experiences from a patient's perspective, I also focused on the extent to which the research attended to the impact of clinicians' assumptions regarding illness aetiology on those experiences.

The secondary purpose for this review was to critically examine what methodological approaches and methods have been used in qualitative research in this area, including the kinds of understandings and insights generated. The aim here was to specifically inform and scaffold methodological decisions, method selection and overall design for the present study.

3.1 Literature search methodology and methods

Interpretive Description (the methodology selected for use in this research, see Chapter 4) cautions against over-reliance on the use of "keywords" as the exclusive approach to identify relevant research. Thorne (2008) argues that keywords reflect "standard" understandings and conceptualisations within a field. It is suggested that authors may use keywords that are common to their discipline to ensure they come up in database searches, but that these might not reflect what is new and different about their research products. Therefore, this methodology encourages researchers to develop a wide repertoire of search resources when conducting a review (Thorne, 2008, 2016). Accordingly, a multi-pronged approach was used in selecting the literature to review for this chapter. This approach is detailed below.

3.1.1 Search strategy

Initially, I scoped the field using intuitive search techniques to familiarise myself with the elements and foundations underlying research into patients' experiences. At this stage, I experimented with different search words relating to the experience of living with and being treated for a chronic illness on EBSCO Health, CINAHL and Google Scholar databases, as well as physical library searches. I undertook physical searches of the library, searching bookshelves near the books I had found using online searches, which helped me find tangibly related knowledge to help orient me towards the research and to challenge my initial thinking. I followed this by reading articles and books that resonated, by examining their reference lists as well as following other more contemporary research, which used them as references (Thorne, 2008). Throughout, I noted the keywords used.

This initial reading stage helped to identify three papers which were particularly influential to my thinking (Thorne et al., 2005; Thorne et al., 2000; Werner & Malterud, 2003), as well as helping me to identify key words for use in a more systematic search of the literature. I conducted this more systematic search with the help of a specialist health research librarian. The full search strategy is included in Box 1.

The search was restricted to a period of five years before the review was undertaken (May, 2015) for two reasons: First, to restrict the studies reviewed to the most contemporary research on the subject; and second, for practical reasons, given the volume of the studies identified on the topic. I acknowledge that restricting the years for the search may have limited my access to earlier, relevant and influential research on this topic. I attempted to address this by utilising the multi-pronged strategy outlined above.

Box 1. Systematic principles search undertaken in EBSCO Health and CINAHL databases, May, 2015.

Qualitative
AND
Patient* OR client OR clients
AND
“Chronic ill*” OR “chronic disease*”
AND
(experience* N8 treatment*) OR (perception N8 treatment*) OR (perceive* N8 treatment*) OR
(perspective N8 treatment*) OR (relationship* N8 treatment*) OR (participation N8 treatment*)
OR (attitude N8 treatment*)
OR
(experience* N8 care) OR (perception N8 care) OR (perceive* N8 care) OR (perspective N8
care) OR (relationship* N8 care) OR (participation N8 care) OR (attitude N8 care)
OR
(experience* N8 therapy) OR (perception N8 therapy) OR (perceive* N8 therapy) OR
(perspective N8 therapy) OR (relationship* N8 therapy) OR (participation N8 therapy) OR
(attitude N8 therapy)
OR
(experience* N8 interaction) OR (perception N8 interaction) OR (perceive* N8 interaction) OR
(perspective N8 interaction) OR (relationship* N8 interaction) OR (participation N8 interaction)
OR (attitude N8 interaction)
OR
(experience* N8 healthcare) OR (perception N8 healthcare) OR (perceive* N8 healthcare) OR
(perspective N8 healthcare) OR (relationship* N8 healthcare) OR (participation N8 healthcare)
OR (attitude N8 healthcare)
OR
(experience* N8 management) OR (perception N8 management) OR (perceive* N8
management) OR (perspective N8 management) OR (relationship* N8 management) OR
(participation N8 management) OR (attitude N8 management)
OR
(experience* N8 psychosocial) OR (perception N8 psychosocial) OR (perceive* N8
psychosocial) OR (perspective N8 psychosocial) OR (relationship* N8 psychosocial) OR
(participation N8 psychosocial) OR (attitude N8 psychosocial)
OR
Qualitative
AND
“chronic ill*” OR “chronic disease*”
AND
(experience* N5 patient*) OR (perception N5 patient*) OR (perceive* N5 patient*) OR
(perspective N5 patient*) OR (relationship* N5 patient*) OR (participation N5 patient*) OR
(attitude N5 patient*)
OR
(experience* N5 client*) OR (perception N5 client*) OR (perceive* N5 client*) OR
(perspective N5 client*) OR (relationship* N5 client*) OR (participation N5 client*) OR
(attitude N5 client*)

3.1.2 Inclusion/exclusion criteria

Papers were eligible for inclusion if they: a) reported a qualitative study or metasynthesis of qualitative studies; b) were focused on the care experiences of people with chronic illness; and c) sought the perspective of people receiving the care.

After applying these initial criteria, articles were excluded if they were:

- a) An evaluation of a specific programme e.g., those designed to educate patients or care providers.
- b) Descriptions of interventions with patients or care providers.
- c) Focused on governance implications e.g., researching how care approaches are understood by patients and care providers for the purpose of making governance recommendations.
- d) Concerned with the lived experiences of people with chronic conditions without reference to their relationships with health professionals.

3.1.3 Data extraction

Each of the included articles was read in its entirety and the article summarised in an Excel spreadsheet. In the spreadsheet, I extracted descriptions of the study, research question and participants. I also extracted a summary of the major concepts covered, and the key findings. Also included were comments on the methodology used, its appropriateness and justification for the research question, and possible methodological implications for this doctoral study (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). In keeping with the non-dualistic, ontological approach of the present study (Broom, 2016a), I commented on whether clinicians' dualistic assumptions about illness aetiology were explicitly considered.

3.1.4 Methodology quality considerations

Consistent with the intent of this doctoral research to offer practical, clinical insights, I centred my methodological critique on the quality aspects of qualitative research that are specifically concerned with the applied clinical implications. Given that qualitative researchers come from diverse methodological, theoretical, and philosophical traditions, it has been argued that it is difficult to produce definitive, explicit claims about what constitutes quality and credibility in qualitative research reports (Thorne & Darbyshire, 2005; Tracy, 2010). Accordingly, I drew on a number of writers and focused on the following four dimensions in assessing the rigour of the analytical product:

1. Credibility and findings fidelity (Sandelowski, 1993; Tracy, 2010)
2. Rigour (Malterud, 2001; Thorne, 2008; Tracy, 2010; Sandelowski, 1993)
3. Reflexivity (Malterud, 2001; Thorne & Darbyshire, 2005; Thorne, 2008; Tracy, 2010)
4. Resonance (Tracy, 2010).

3.2 Literature search findings

The screening process and search results are illustrated in Figure 2. In total, 72,050 article titles and abstracts were identified and reviewed for relevance. Following this initial review, 72,000 were excluded because the paper was either quantitative (e.g., randomised controlled trials of treatment efficacy) or was not concerned with the experience of people who were living with, and being treated for, a chronic condition. The full text of 50 articles was retrieved, following which eight were excluded as they did not meet the initial inclusion criteria. After applying the exclusion criteria, a further 31 articles were excluded.

Including the three papers identified in the early scoping, a total of 14 papers were included in the review. The papers identified in the systematic search included papers that were exclusively concerned with the experiences of people receiving care, as well as those which also included the perspective of clinicians. This is because at the outset of the research, I contemplated formally including the perspective of experienced clinicians as part of the study, and therefore these studies were deemed relevant for the purpose of scaffolding the research design.

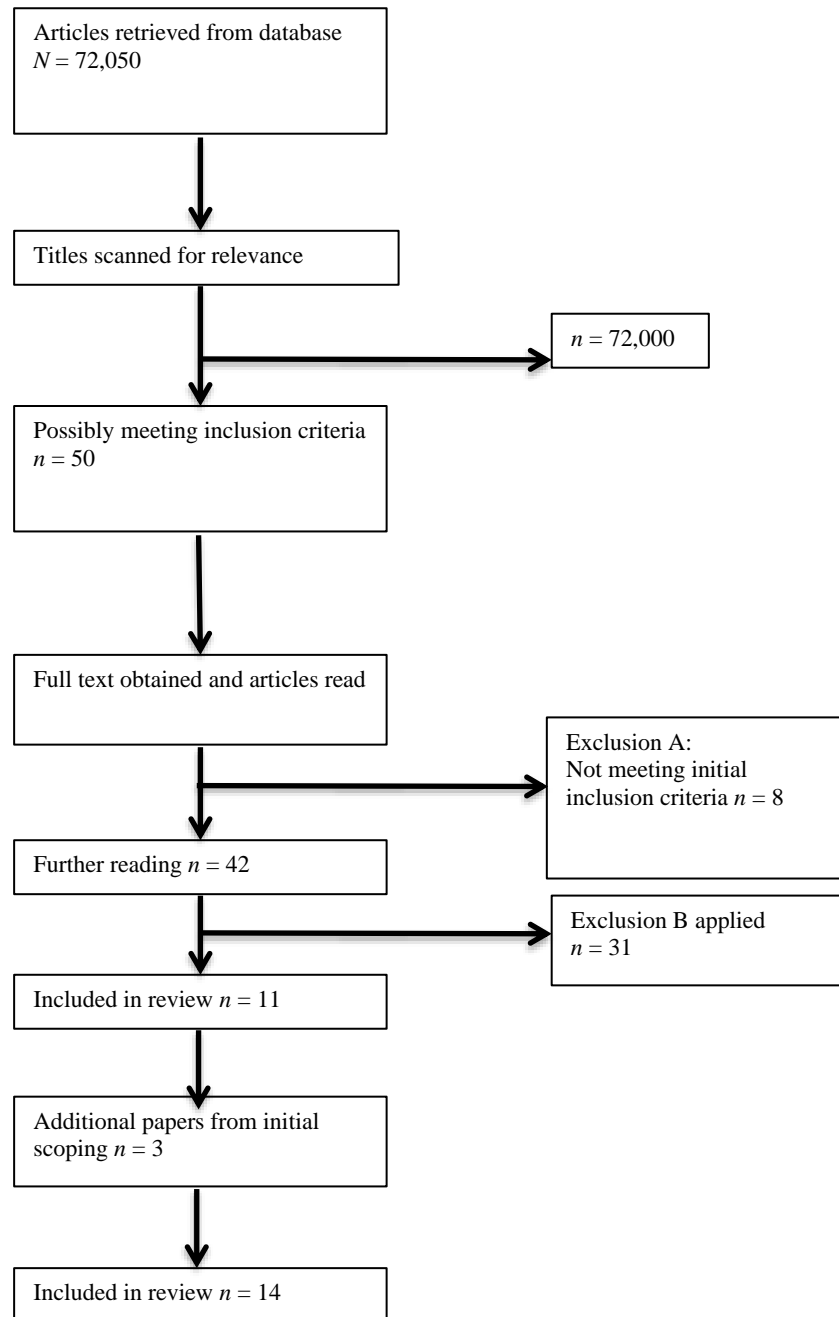


Figure 2. Literature search strategy and results.

Table 1 provides an overview of the 14 studies reviewed in-depth. The synthesis of findings is divided into three parts. In Part 1, I provide a substantive synthesis of what is known, from the studies reviewed, regarding the care experience of people who suffer from chronic conditions. In Part 2, I specifically focus on whether the clinicians' worldview of disease aetiology was examined, and if so, how that was addressed in the research. In Part 3, I focus on the methodological implications for the present research. In this section, I critique the methodologies used and relate them back to the present study.

Table 1

Summary of Included Papers

Authors	Research question/purpose	Methodology/ methods	Participants description	Methodology/methods commentary	Key findings
(Ali, Vitulano, Lee, Weiss, & Colson, 2014)	To gather insights about the experiences of patients who identified themselves as having chronic Lyme disease (CLM) in the healthcare system.	Hermeneutic phenomenology Individual interviews.	Twelve patients identifying themselves as having CLM. Both those 'diagnosed' and 'self-identified'.	Described as using purposive sampling and hermeneutic phenomenological methodology. However, the description of the analytic process is more consistent with thematic analysis and the interview guide used appears relatively structured which is somewhat inconsistent with phenomenology. Good transparency about how their professional background may have influenced their findings.	Four major themes emerged from participants' descriptions of their experiences and perceptions. 1. Changes in health status and social impact of CLM including, not believed and suffering and living impaired daily lives and professional limitations; 2. Doubts about recovery and the future; 3. Contrasting doctor-patient relationships, with two divergent types of doctor-patient relationships; either exceptionally supportive, or uncaring and dismissive; 4. Seeking unconventional therapies to treat CLM.
(Cocksedge, Greenfield, Nugent, & Chew-Graham, 2011)	To explore the experiences of GPs and patients of the management of chronic illness with a particular focus on holding relationships in the context of the patient centred model of the UK.	Semi-structured interviews and analysis guided by the constant comparative method of Corbin and Strauss.	GPs with over 5 years' experience and their patients. In total 11 GPs and 14 patients were interviewed.	Good description of methodology and approach taken to both construction of the structured interview guide and analysis. Used category saturation as justification for recruiting decisions. Analysis limited to their pre-existing lens of holding relationships.	Five themes were identified in relation to the holding experiences. Holding - All doctors reported doing that and saw it as the bread and butter for their work - just holding without expectation for patients to get better. Patients didn't use the term but described the importance of the one significant relationship with a GP. The value of holding - the benefits patients' report of the value of being listened to. For the doctors it was an important part of their own job satisfaction. Danger of holding - if patients become dependent and the possibility of missing new and possibly unrelated symptoms. Barriers to holding – Political expectations of excessive measurement of performance indicators. Judgement on the other – To do with establishing close friendship-like connections.

Authors	Research question/purpose	Methodology/ methods	Participants description	Methodology/methods commentary	Key findings
(Håkanson, Sahlberg-Blom, & Ternestedt, 2010)	To gain in-depth understanding of the patient experiences of persons with irritable bowel syndrome (IBS) in their encounters with healthcare providers for the purpose of improving care and disease management.	Interpretive Description.	Nine individuals, two men and seven women were recruited from a gastroenterology outpatient clinic in a Swedish hospital.	Provided rich and plausible descriptions of the care encounter (see examples below). Their findings resonated emotionally.	<p>The study revealed two oppositional core positions, in relation to participants' encounters with healthcare.</p> <p>The first position, "experiencing unsupportive encounters" included three themes of experiences shaped by 1. Being exposed to various faces of humiliation: not being taken seriously, accused of exaggerating or imagining their illness which leads them to start questioning their own illness experience; 2. Being insignificant as a person: not feeling recognised as unique individuals and their experience as suffering from symptoms not acknowledged; 3. Being abandoned by healthcare. The participants believed that healthcare professionals regarded IBS patients as being of low priority because IBS was not a "real" disease.</p> <p>The second and less prominent core position, "experiencing supportive encounters," included one theme, "being acknowledged as a person," which represented experiences that were shaped by mutuality, understanding, and acknowledgment of the person's lived experience of illness.</p>
(Hudon et al., 2013)	To investigate the patients' perceptions of family physicians enabling attitudes.	In-depth interviews followed by thematic analysis following the principles outlined by qualitative description.	Thirty patients, 35 to 75 years of age presenting at least one common chronic disease, which are most frequently seen in primary care.	Their approach approximated positivism. Despite extensive use of quotes for substantiating their coding approach, emphasis was given to the frequency of mentions as justification for findings rather than analytical insight. Further, they do not explain how patients were selected in relation to their phenomenon of interest.	<p>Six themes were identified and explored.</p> <ol style="list-style-type: none"> 1. Developing a partnership with family physician over time is a key element to promoting their empowerment. Building a relationship based on trust. Making patients feel comfortable, showing empathy and respect, informing, providing results taking patient preference into account; 2. Promoting patient interests in the healthcare system, fostering collaborations and continuity of care, and accessibility to care; 3 Starting from the patient situation, knowing the antecedents, knowing the feelings, repercussions, expectations, personality, family, and life context; 4. Legitimising illness experience, recognising suffering and managing emotions; 5. Acknowledging and prompting the patient's expertise. Fostering greater awareness and self confidence; 6. Helping patients maintain hope.

Authors	Research question/purpose	Methodology/ methods	Participants description	Methodology/methods commentary	Key findings
(Koch, Wakefield, & Wakefield, 2015)	To conduct a systematic review of the literature on patients' perceptions of facilitators and barriers to effective management of Multiple Chronic Conditions (MCC).	Systematic review of the literature.	Thirteen articles met the inclusion criteria. Study sample size ranged from 11 to 98 patients with a mean of 35 participants.	Rigorous documentation of their systematic approach. The synthesis appears overly focused on reporting the methods of included papers and therefore may have missed the opportunity for a more in-depth synthesis of the substantive findings.	<p>Nine barriers identified: 1. Emotional impact; 2. Complexity of managing multiple condition; 3. Physical limitations; 4. Financial constraints; 5. Complexity of communicating with healthcare providers.; 6. Inadequate family and social supports; 7. Logistical challenges; 8. Complexity of medication management; 9. Lifestyle changes.</p> <p>Four facilitators identified: 1. Health system support; 2. Individualised care education and knowledge; 3. Informal support from family and social systems; 4. Having personal mental and emotional strengths.</p>
(McCormack, Karlsson, Dewing, & Lerdal, 2010)	To explore person-centeredness for the purpose of informing the understanding of person-centred nursing.	Qualitative metasynthesis guided by a hermeneutic and interpretative approach and framed in a person-centred framework which was developed for the purpose of an experimental study.	Data derived from four unrelated research studies which were done with clients with long term health conditions by the authors of this article. These studies did not have a main aim of researching person-centeredness. The studies were done by the authors in Norway, England and Ireland, with people with long term conditions treated in different therapeutic contexts, which included nursing homes, private homes, psychiatric homes and community hospital.	The framework was applied retrospectively. The theoretical framework is well explained and the analytical steps are transparent. Use of thick quotes to justify and ground findings. An article that can be described as rigorous and credible. Very little by way of reflexivity, specifically how their previous involvement with the data may have impacted their analysis.	<p>The findings were organised along the following five dimensions:</p> <p>Prerequisites: Being committed to being person-centred, having a supportive environment and organisational culture, with technically competent staff.</p> <p>The care environment: Concerned with the challenge of moving away from the culture of 'task' work towards power sharing, mutuality and trust.</p> <p>Care process: Concerned with the importance of a high quality relationship between healthcare workers and patients. Despite the PCC framework the dominant focus remained on tasks and procedures.</p> <p>The impact of the practice context: Challenges associated with the organisational culture and context. The analysis of the data from the four studies provide insight into the challenges of developing a PC practice and impact of different cultures on this.</p> <p>Relationships between different constructs in the person-centred nursing framework: Prioritising competence over interpersonal skill. Focusing on technical competence and little attention paid for knowing self which may be crucial to person-centred practice.</p> <p>Conclude that developing person-centred practices and cultures are ongoing, not a one-off task. It is more than focusing on prerequisites such as personal skills and competence. They argue that it must include attention to the development of the practice context and cultural elements and pattern within.</p>

Authors	Research question/purpose	Methodology/methods	Participants description	Methodology/methods commentary	Key findings
(Morales-Asencio et al., 2014)	To improve the design of case management services for chronic conditions.	Semi-structured interviews followed by qualitative inductive content analysis.	Eighteen patients with complex chronic diseases and their family caregivers, selected by purposeful sampling in primary health care centres in Andalusia.	Provided a rigorous description of their approach and analysis, focusing on coding reliability but neglected to explore aspects of their data which could have added to the richness and resonance of their findings.	In seeking to delay the loss of quality of life, coping mechanisms, the proactivity of providers, family support, the adequate provision of information and the continuity of patient care were shown to be the main areas in which interventions should be targeted during the course of chronic diseases.
(Sutanto et al., 2013)	Developing a comprehensive conceptual framework to explain the experiences and perspectives of adults living with systemic lupus erythematosus for the purpose of developing strategies to deliver patient-centred care of this illness.	Thematic synthesis.	Forty-six qualitative studies involving more than 1,385 participants.	Their approach is rigorously described but the analysis is somewhat limited in that they have not attended to the possible impact of the methodology used in the studies on the types of findings generated.	Five themes were identified: 1. Restricted lifestyle including sub-themes concerned with fatigue, pain and disruptive episodic symptoms; 2. Disruptive identity and achievement of diagnostic closure once diagnosed; 3. Societal stigma and indifference and illness trivialisation because of invisible symptoms; 4. Gaining resilience when supported and by developing positive attitudes; 5. Treatment adherence.
(Phillips et al., 2014)	To understand the perspectives and experiences of patients, carers and clinicians about the experiences of patients who are actively engaged in inter-professional care. Where the patients are in the patient-as-professional role.	Purposeful sampling. Interviews and focus groups. Thematic analysis used to identify patterns across the data sets using two independent researchers.	Two-phased study. Phase one, 50 people with chronic illness and 5 of their caregivers. Phase two involved 14 clinicians who self-reported experience in supporting patients to self-manage.	The methods used appear consistent with the practice orientation of the research question. However, there is no justification for the lack of an overarching methodology; rather, a collection of methods and no theoretical considerations or attempts to link with theoretical frameworks which may help explain the findings.	Patient participants identified the factors which impact on the development of a strong relationship - time constraint and lack of coordination between clinicians were barriers. They thought it wasn't for everyone. The findings from the clinicians are grouped as four themes. 1. The patient's role to contribute knowledge. In particular, information related to their experience of their chronic disease and its management; 2. The clinician's role: solve problems, follow up and provide long term support; 3. The importance of the clinician-patient relationship: building a strong relationship built on trust and sufficient time given to build that relationship; 4. Ramification of the patient as professional role: some clinicians were concerned that this would result in the need for longer consultations, and maybe overwhelming for some.

Authors	Research question/purpose	Methodology/methods	Participants description	Methodology/methods commentary	Key findings
(Tlili et al., 2015)	To provide the perspective of ordinary Tunisians treated for their diabetes and hypertension in public health clinics. The researchers sought to explore the patients' understanding of their disease aetiology and their ideas about biomedical treatment and its implications.	General qualitative methodology using interviews and observations thematically analysed using software.	Twenty-four patients with diabetes and/or hypertension. A subset of 12 family members was also interviewed. A small separate sample of clinic staff was also interviewed.	The authors explain that there is very limited understanding of qualitative research in their region and are transparent about their lack of expertise in conducting this type of research and how it might have influenced their findings.	Two key themes were identified. First theme of patients being nostalgic to a simpler life and modern life being the cause of the illness. A second theme has a more direct bearing on health policy and clinical practice, and concerned communication. Patients were continually frustrated by perfunctory and sometimes brusque attention they received from clinic staff. They sought a more personal relationship with their doctors. Health personnel in turn were frustrated by what they saw as the inattention of patients to medical advice and instruction.
(Tarrant, Windridge, Baker, Freeman, & Boulton, 2015)	To explore chronic patients' experiences of discontinuities in care. Their analysis was informed by the theoretical framework of 'candidacy'. Candidacy is described as the way people's eligibility for medical care is determined by the health gate-keepers once access is negotiated between individuals and health services.	Secondary analysis of the original interviews which followed a narrative structure. Followed the theoretical framework of candidacy.	Fifty patients recruited from general practices in the UK. Seventy per cent of participants had at least one chronic health problem and a third suffered from multi-morbidity.	Excellent detail of the methodology used and the steps followed in recruitment and in analysis. Transparent about limitation of not involving doctors in this research.	Three themes were identified. Falling through gaps and candidacy: those who experience gaps also experienced difficulty in getting the health system to engage with them as eligible recipients of care. Not about the nature of the illness, but the failure of the system to take responsibility. Bridging gaps in care: patients taking upon themselves to appearing as 'credible patients'. Taking it upon themselves to become more active and demand care. Unresolved gaps in care: none had a health professional that they could rely on and all felt being unwanted or rejected by healthcare providers and the system.

Authors	Research question/purpose	Methodology/ methods	Participants description	Methodology/methods commentary	Key findings
(Thorne, Ternulf Nyhlin, & Paterson, 2000)	To compare the experiences of two group with different chronic diseases Type 1 Diabetes and Environmental Sensitivities to see if there are common underlying health professionals' values and attitudes that influence the experience of living with the illness and negotiating care.	Qualitative secondary analysis.	Twenty-two Canadian individuals with longstanding diabetes and 13 Swedish women diagnosed with serious adverse reactions to environmental agents.	Detailed description of the use of analytic expansion where researchers familiar with the studies use the data to answer questions that are logically aligned with the original questions alongside the use of constant comparative analysis. Their use of verisimilar quotes is used to illustrate the consistency of the themes across the cultures and types of illnesses researched. They use quotes in a way that achieves both fidelity and resonance. However there is very little by way of reflexivity.	<p>Six themes were identified and explored.</p> <p>Retention of expertise: How clinicians cling to the role of the expert within the encounter. Professionals assuming their own opinion about both illnesses, even though patient's been managing it for years.</p> <p>Control of information: Controlling the information to which the patient has access as well as Discrediting ridiculing and dismissing patients' concerns about treatments and side effects.</p> <p>Assumptions about biomedical superiority: Healthcare professionals demonstrating little appreciation of the holistic aspects of the chronic illness experience.</p> <p>Privileging disease information above quality of life: "Although health care professionals are ostensibly interacting with the individual who happens to have a disease, patients often reported that health care professionals treated them instead as diseases who happen to be carried by individuals" (p. 306).</p> <p>Psychological labelling of patients' behaviour: A common feature of the chronic illness experience was having one's physical symptoms interpreted as signs of psychological symptoms. Used in most cases to belittle and discount patients' experiences.</p> <p>Punitive gatekeeping: Restricting access to systems and structures based on clinicians' views of disease legitimacy.</p>
(Thorne et al., 2005)	In-depth exploration of cancer patients' articulation of their experiences with helpful and unhelpful communication in the context of the care they received and what they perceive as constituting effective communication in this context.	Interpretive Description.	Two-hundred patients with diverse cancer experiences.	Used a variety of data collection methods including interviews, focus groups and email correspondence. Logical insights generated justified by select and life-like quotes. Reflexive in how they comment on the findings impact on their understanding of the topic.	<p>These findings are concerned with contrasting the theme of 'being known' with all the other themes "“Being known, therefore, as we refer to it here, reflected an acknowledgement of elements of one's personhood within the context of the inherently difficult nature of this disease”" (p. 891).</p> <p>Being and not being known: Being known was a dichotomous valence within the set. Being known seen as holistic - focusing on the patient as a person. Where the clinical gaze from role/function to the person. Not being known was about the technical orientation of the clinical encounter. The authors conclude that communication that conveys a sense and feeling of being known must be done in respect to the person's uniqueness and personhood in the context of cancer care and that there is no one size fits all.</p>

Authors	Research question/purpose	Methodology/ methods	Participants description	Methodology/methods commentary	Key findings
(Werner & Malterud, 2003)	To explore the ways women who suffer from medically unexplained conditions “work” in order to be taken seriously when consulting doctors.	Semi-structured interviews. Analysis following Giorgi phenomenological analysis focused on the gendered dimensions of the experience.	Ten Nordic women of varying ages and background suffering from chronic muscular pain. Utilised purposeful sampling covering different backgrounds of illness experience, health system experience, employment and age.	Detailed and transparent description of their approach to recruitment and analysis. The findings generated are illustrated by excellent quotes which illustrate the tacit dimensions of patients’ experiences. Less explicit regarding authors’ reflexivity. Could have benefited from authors being reflexive about how their feminist orientation may have impacted on their findings. Also attending to the impact of physicians’ view of disease aetiology could have added another dimension to the interpretation.	Women patients’ activities before and during the consultations with doctors were interpreted as demonstrating that they worked hard to appear as credible patients by making their symptoms appear visible, real and physical. The authors comments that the women’s efforts reflected a subtle balance to come across as “just right” (p. 1414) to their treating physicians. This was described in their efforts of appearing not too strong or too weak, too sick or too healthy or too smart or too disarranged. The authors conclude that their “findings indicate that the combination of pain and gender demand specific forms of expression if women with medically unexplained disorders are to be perceived as credible patients” (p.1417).

3.3 What do the reviewed studies reveal about the care experiences of people suffering from chronic conditions?

It is increasingly acknowledged that care relationships are of particular importance in the context of caring for people who suffer from chronic conditions. In the technological and guideline-driven medical system, it has been argued (Johnson, 2013; Miles, 2009b) that encounters with disease-focused medical professionals may have the unintended consequence of adding to the suffering of the person who is already ill. For example, Gergel (2012) argued that a person can end up feeling objectified and reduced to being the “vessel” of the disease, where the “whole” of one’s self has been lost somewhere.

The science of medicine has resulted in tremendous success in the treatment of acute conditions and infections (Johnson, 2013; Miles, 2009a; Sheldrake, 2012). However, globally, and in particular in advanced countries, the health system is experiencing an avalanche of patients presenting with multiple chronic conditions. Chronic illnesses are a leading cause of death and disability internationally and worldwide, accounting for 60% of all deaths (Miller, Bakas, Buelow, & Habermann, 2013). In countries like the US, one in two adults has at least one chronic illness, and seven in ten US deaths are the result of a chronic illness. In the US alone, chronic conditions account for 75% of the healthcare costs (Johnson, 2013).

Arguably, because of the ongoing nature of chronic illness and conditions, which involves many interactions with healthcare professionals, the clinical relational aspects are of particular importance in this context. Accordingly, in most of the studies reviewed for this chapter, the quality of the patient–clinician relationship is identified as the most important element of the care experience.

I have divided the insights obtained from the studies reviewed into two key parts in this section:

- Negative experiences/barriers to better care
- Facilitators/enablers of positive encounters

3.3.1 Negative experiences/barriers to better care

Perhaps unsurprisingly, many of the themes identified in this review as exemplifying negative care relationships, echo much of the criticism levelled at the impact of Cartesian dualism and over-reliance on EBM-derived care protocols outlined in the

previous chapter. The themes identified here build and elaborate on the general criticisms outlined previously. I have grouped these themes under the following headings:

- The more complex the condition is, the more negative the care experiences seem to be.
- Disease-centred care experiences.
- The impact of the care experiences on the patients' sense of self.
- Clinicians overlooking that patients are active agents who are constantly evaluating the care they are receiving.

3.3.1.1 The more complex, the more negative

The articles reviewed in this chapter appear to indicate that the most negative care experiences were those of people who suffered from conditions that are hard to diagnose and therefore seen as “complex” (Sutanto et al., 2013; Tarrant et al., 2015). These include people who suffer from multi-morbidity, or from conditions that were difficult to diagnose or “undiagnosable” (Ali et al., 2014; Håkanson et al., 2010; Tarrant et al., 2015; Thorne et al., 2000; Werner & Malterud, 2003).

Across the studies mentioned above, clinicians were experienced as questioning the person's legitimacy as a patient. The themes commonly elucidated patients' experiences of being ridiculed, minimised and not taken seriously by medical professionals. This was the case for people with illnesses that are hard to diagnose but do have a clear “aetiology”. For example, people who suffered from the “diagnosable” systematic lupus erythematosus (Sutanto et al., 2013) spoke of their experiences of living with unexplained symptoms, and consequently of being ignored by clinicians, as their symptoms were hard to explain and diagnose.

These experiences were also mirrored for those who did not have a clear diagnosis and aetiology. For example, Ali et al. (2014) study investigated the experiences of patients who identified themselves as having chronic Lyme disease (an “undiagnosable” northern American illness). Patients in this study described their experiences of clinicians who were uncaring and dismissive and did not listen to or believe their accounts of their symptoms as illustrated in the following quote: “I couldn't continue to see someone who didn't believe I have a disease that I know I have. You know, it's a

chronic disease and I would see him every year for my annual exam and he didn't believe me" (Ali et al., 2014, p. 8).

This sense of not being believed in the absence of a clear aetiology resonated with narratives across a range of illness groups (e.g., chronic pain, chronic fatigue syndrome, Lyme diseases, IBS, etc.). Lacking a clear pathophysiological basis for symptoms may contribute to some illnesses being perceived as less real than others. Indeed, Tarrant et al. (2015) used words such as legitimacy when describing patients, referring to clinician perspectives that some patients were deemed as "legitimate" and others were not. Those who were not considered legitimate, and who seemed to experience the most gaps in care, were those who suffered from complex conditions and multi-morbidity. The authors describe how, "common to all these accounts was a feeling of being unwanted or rejected by health care providers and shut out by the health system" (Tarrant et al., 2015, p. 85). In a Nordic study with women suffering from unexplained chronic pain, the authors also described how participants had to invest energy, time and work at appearing credible in their encounters to communicate to doctors that their symptoms were socially visible, physical and real (Werner & Malterud, 2003). They described how these women were conscious of their physical appearance aligning with their doctor's expectations of what a person suffering from pain should look like: "Sometimes I feel that I should look groggy, my face should be grey, and I should wear no make-up; that I perhaps appear to be too strong (I, 37 years)" (Werner & Malterud, 2003, p. 1414).

An investigation into the experiences of people who suffer from IBS, an illness that has no clear "aetiology", further echoed these experiences (Håkanson et al., 2010). Håkanson et al. (2010) described a theme concerning "exposure to the various faces of humiliation" endured by participants (Håkanson et al., 2010). In this study, patients described how they experienced health professionals "telling them to calm down or to stop being hysterical about their symptoms...they described feeling accused of exaggerating or even imagining their illness" (Håkanson et al., 2010, p. 1120). Indeed, participants in this study described their experiences as feeling "abandoned by health care" (p. 1121). They believed that healthcare professionals regarded IBS patients as being of low priority because they considered IBS as not a real disease as there was no objective indication of a serious underlying reason for the symptoms, which led to them questioning their own illness experience.

Various forms of psychological labelling when an illness did not appear to have a clear aetiology was prevalent across the studies reviewed. Psychological labelling of patients' behaviour was a common feature of the chronic illness experience of people suffering from environmental sensitivities (Thorne et al., 2000), unexplained chronic pain (Werner & Malterud, 2003) and, to a lesser extent, by those suffering from IBS (Håkanson et al., 2010). Patients experienced this labelling as being used to belittle and discount their illness experiences, which, in turn, resulted in them experiencing self-doubt and even shame.

3.3.1.2 Disease-centred care experiences

Where there was a diagnosis of a specific aetiology, and patients were deemed "legitimate", the care experiences were described as disease-centred, with disease information privileged above the quality of care (Thorne et al., 2000). For example, in a study investigating helpful and unhelpful communication in the context of cancer care, one participant described how: "I mean he - the oncologist - even said to me, 'you know, I put all my data into a computer and I come up with what's the best recommendation for you, you know'. And I'm thinking well. What are you putting into the computer?" (Thorne et al., 2005, p. 891). Disease-centred approaches to care were prevalent throughout the studies reviewed. They were exemplified through descriptions of poor communication and access barriers with healthcare providers (Koch, 2015), as well as task-focused clinical environments (McCormack et al., 2010). In the context of multi-morbidity, patients reported experiences of fragmentation, a lack of coordination and communications between care providers, as each specialist area focused on the "disease" under their domain of care (Tarrant et al., 2015).

In some cases, such as in Thorne et al. (2000), patients' points of view, about what it is they want to achieve for themselves in the context of their lives, are viewed as not relevant. The authors describe how "when the participants attempted to modify their adherence to prescribed regimens in order to live as well as possible, their efforts were typically met with considerable resistance and suspicion by health care professionals" (Thorne et al., 2000, p. 307). I would argue that experiences such as these communicate to patients that their own judgement and competency are unimportant because they are not the experts in treating their illness despite being the ones who live with it. Furthermore, from the studies reviewed, it appears that in addition to minimising the competency of patients under this "disease focused" care, medical professionals may also be reluctant to promote self-care (Koch et al., 2015; Morales-Asencio et al., 2014).

This observation resonates with a growing contemporary body of work that highlights the tensions practitioners experience in letting go of control over patients, and in acknowledging patient expertise in managing their own chronic conditions (Mudge, Kayes, & McPherson, 2018).

In one of the studies reviewed for this chapter, the experiences of two groups with different chronic diseases (Type 1 Diabetes and Environmental Sensitivities) were compared to see if health professionals shared common underlying values and attitudes that influenced patients' experiences of living with the illness and negotiating care. Thorne et al. (2000) identified "retention of expertise" as a key theme. This referred to the way clinicians held on to the role of the expert within the encounter, assuming their own opinion as superior, even though patients had been managing their condition for years (Thorne et al., 2000).

It is important to note that these experiences were not confined only to affluent English speaking countries, but were mirrored in cross-cultural contexts as well. In a Tunisian study, Tlili et al. (2015) found that doctors were experienced as giving insufficient time and attention to listen to patients and as only focusing on their symptoms. They found that Tunisian health professionals, in turn, had their own views about the knowledge and behaviour of the patients and families they saw. Data revealed a number of judgemental views and where doctors minimised patient competencies. For example, the authors described how, during the research observation, a patient was telling the doctors that he had monitored his condition carefully and had managed to reduce his intake of the medication. Tlili et al. (2015) reported how, in reply, the doctor said, "You are not a doctor, what permits you to make these decisions?" (p. S35).

3.3.1.3 Impact on patients' personhood

Perhaps unsurprisingly, the care experiences described above were reported to result in a negative impact on patients' sense of self. One of the themes reported in the Håkanson et al. (2010) study of patients suffering from IBS was "feeling insignificant as a person". The authors described how the clinical focus on investigation, and procedural care, resulted in participants reporting feeling insignificant, where views of their own condition were not considered and their suffering not acknowledged in any way. The authors interpreted this theme as covering feelings derived from encounters characterised by the absence of both inter-subjectivity and openness toward the patients' experiences. "The burden of illness is enhanced when the person behind the 'patient' is

not seen, not invited to share, and not allowed the weakness of being a help-seeking person with a lived experience” (Håkanson et al., 2010. p. 1121).

Negative labelling by clinicians does not go unnoticed by the patients themselves. This, in turn, impacts further on their sense of self. For example, women who suffered from unexplained medical symptoms reported negative treatment experiences where they struggled to be perceived by their treating physicians as suffering from a physical and somatic illness rather than assumed to be, and therefore labelled as, mentally unbalanced (Werner & Malterud, 2003).

3.3.1.4 Patients are constantly assessing the care experiences

When reviewing the articles as a group, it was striking to see how the data illustrated the extent to which patients were constantly assessing the care experiences and forming their own judgements about the care they received. These assessments appeared to go unnoticed by the treating physicians and medical professionals. For example, in the Tunisian study, an older woman spontaneously compared the care she received in urban and rural clinics (Tlili et al., 2015). Patients in these studies appeared to be forming their own decisions with respect to their own care, based on their personal preferences and belief systems, which at times, were not consistent with those of their treating healthcare professionals (Ali et al., 2014; Thorne et al., 2000; Tlili et al., 2015).

This inferred theme highlights the co-constructed nature of the therapeutic relationship. With the growing recognition that clinicians’ attitudes, beliefs and feelings play a significant role in influencing patients’ experiences and outcomes (Kayes, Mudge, Bright, & McPherson, 2015), it is possible that becoming aware of the active decisions patients make about their own care could help shift the beliefs of clinicians and help them to recognise the role they play in influencing their patients’ behaviour. Becoming more cognisant of this may help pivot clinicians towards working *with* patients – as opposed to deciding *for* them, something that is increasingly being advocated (Mudge et al., 2018).

3.3.1.5 Summary of negative experiences/barriers to care

To summarise, negative experiences in the studies reviewed fell into four key themes. The first theme was concerned with *complexity of condition*. Across the studies reviewed, the more negative care experiences were associated with more complex conditions, and with conditions that had no clear aetiology. There were many instances of persons experiencing “ridicule” and “minimisation of their suffering” under this

theme. In turn, patients took actions to appear more credible so that they could get the care they needed.

The second theme concerned *disease-centred experiences*. This was particularly prevalent in the experiences of people who had illnesses with a specific aetiology. Data and data analysis within the papers identified that patients experienced care that privileged disease information over quality of care, as well as poor communication and fragmentation, where specialists were only concerned with illnesses and symptoms that fell under their domain of expertise. These experiences seemed to indicate that disease-centred approaches might result in minimisation of the competency of patients in caring for their own illness and conditions.

The third theme was concerned with the *impact of these experiences on the persons' sense of self*. Negative experiences were reported to result in patients feeling reduced and insignificant as their personhood went unacknowledged by clinicians who saw them only as patients, or as carriers of symptoms.

The final theme was concerned with the *patients' own assessment of the care experiences*. This theme was not identified in any of the studies *per se*, but could be inferred from them, as identified in Section 3.3.1.4. The studies provided an insight into the co-constructed nature of the clinical relationship, albeit tangentially. Of particular importance was that these assessments appeared to inform patients' decisions about their own care, and whether or not to follow the advice and instructions they were given, which may have influenced their treatment outcomes.

3.3.2 Enablers/facilitators of positive encounters

Instances of positive encounters were less frequent in the literature reviewed, possibly because of the research focus of the articles. See for example, Werner and Malterud's (2003) explicit focus on the women's negative experiences of consultations, "rather than the many accounts of encounters characterised by mutual trust and respect" (p. 1416). When positive encounters were described, they were concerned with the quality of the therapeutic relationship, and the patients' sense of being acknowledged first as a person, and then as a patient (Ali et al., 2014; Cocksedge et al., 2011; Håkanson et al., 2010; Hudon et al., 2013; McCormack et al., 2010; Sutanto et al., 2013; Thorne et al., 2005). Positive encounters appeared more prevalent with clinicians who were able to build relationships with patients based on trust, who demonstrated empathy and respect, sincerity and engagement (Hudon et al., 2013).

Empathy, effective communication and tailored, person-centred approaches were the common denominator in most of the positive clinical encounters described. Authors such as McCormack et al. (2010), in their interpretation of secondary analysis of four different studies, suggested that high quality relationships between healthcare professionals and patients are paramount in the effort to move towards person-centredness. McCormack et al. (2010) highlighted that, in their study, the dominant focus was on technical competence which was prioritised over other aspects of competence “which may be crucial to person-centred practice, such as knowing self” (McCormack et al., 2010, p. 628). The studies reviewed illustrate that when emotional support is offered from clinicians, it encourages a positive outlook by the patient. This results in patients who suffer from difficult to diagnose conditions such as lupus (Sutanto et al., 2013) feeling more motivated to persevere and cope, as well as more informed and empowered to manage their illness.

In the studies reviewed, participants reported strong feelings about what they evaluated as high-quality care, and the characteristics of physicians that they had found most helpful. For the purposes of this review, I have grouped the themes identified under the following headings:

- Ability to interact with the patient as a person.
- Being respected as individual patients.
- Respecting and recognising the patients’ own agency and competency.

3.3.2.1 Ability to interact with the patient as a person

Participants in the included studies were very clear about the positive impact of the experience of being treated as persons rather than patients. They spoke of being seen as more than just an illness, as a person with a history and a unique context. They elucidated the positive experience of being treated by clinicians who demonstrated interest in those aspects of their personhood. For example, in the investigation into the experiences of patients who suffered from IBS, the single positive theme the authors identified was concerned with “being acknowledged as a person” (Håkanson et al., 2010). This theme represented experiences that were shaped by mutuality and understanding, where physicians acknowledged the person’s lived experience with the illness, as illustrated by the following quote of a participant describing her meeting with a physician who believed her: “And then I was sort of touched to tears, because, God, someone’s taking me seriously. I get so incredibly grateful that someone is actually

ready to believe in me and devote time to me, it felt completely incredible” (Håkanson et al., 2010, p. 1122). Thorne et al. (2005) used thick descriptions to underscore the power of positive care experiences by illuminating the ways patients articulated feeling how important their wellbeing was to the clinician: “She was so compassionate and she made me feel that, um my welfare mattered most to her in the world right at that moment... I thought I was loved” (p. 891).

The literature reviewed suggests that continuity of care may facilitate the experience of feeling treated like a person in the clinical encounter. Patients with long-term, chronic conditions were reported to value the ability to form long-term relationships with one GP in a context where they felt cared for and listened to (Cocksedge et al., 2011).

Further, in an investigation of patients’ perceptions of what constituted an enabling attitude by family physicians, the investigators found that developing a partnership with a family physician over time was a key element of promoting patients’ “empowerment” (Hudon et al., 2013). However, even though continuity of care may be one element that could facilitate the experience of being cared for as a person, it did not guarantee it (Hudon et al., 2013).

From the literature reviewed, it does not appear possible to provide a prescription of what clinicians “should” do to create the experience for “patients” of being treated as a “person”. Descriptions of what clinicians did, or how they communicated and behaved were varied, but the resulting positive feelings or experiences were consistent, albeit achieved in different ways.

In their large-scale investigation into helpful and unhelpful communication in the context of cancer care, Thorne et al. (2005) came to recognise how therapeutically beneficial for cancer patients it was when they felt acknowledged by their clinicians for elements of their personhood within the context of this difficult disease. Patients reported different cues from healthcare professionals, such as eye contact, touch and remembering personal details that they felt were important. However, there were variations of how these cues were interpreted. In fact, the authors concluded that, “within the cancer care context, ‘being known’ represents a wide range of unique manifestation of the common desire for human connection” (Thorne et al., 2005, p. 893).

3.3.2.2 Being respected as individuals

The theme above speaks to the patient being recognised as a person first, which seemingly cannot be attributed to any single behaviour or pattern of behaviours by a health professional (Thorne et al., 2005). However, the literature reviewed suggests that the experience of receiving care that patients perceived as being individualised to them, may be one way of achieving this. Individualised care was conceptualised as a possible vehicle, which facilitated the patients' experience that they were treated and respected as individuals. For example, patients seemed to interpret how healthcare professionals acted within clinical situations as exemplifying individualised care. These were clinicians who took all factors into account in treatment and treatment recommendations, factors such as knowing the history, the person's personality and other aspects relevant to them (Hudon et al., 2013). Patients made astute observations about these physicians such as, "She knew enough about me to give me the information she knew would be right for me" (Thorne et al., 2005, p. 892).

This individualised care and information may be experienced as respectful of the persons' agency and competency as patients, and therefore enabling greater ownership for their own care. For example, in Hudon et al. (2013), one participant described how their physician "always had the right way to make me understand things that I really did not want to understand" (p. 6), which the authors used as an example of the ways in which physicians helped patients become aware of their strengths and helped them develop confidence and expertise in self-care. In their systematic literature review, Koch et al. (2015) identified health information and education which is tailored to patients as individuals, as a key facilitator of their ability to effectively manage multiple chronic conditions.

3.3.2.3 Recognising and respecting the patients' own expertise and agency

The third theme identified as characteristic of positive encounters, in the literature reviewed, can be seen as a possible outcome of the previous two. By seeing patients as people first, tailoring information and treatment decisions accordingly, it is possible that patients feel recognised and respected for their own competency, expertise and agency.

The literature reviewed suggests that recognising the agency and competency of patients was increasingly seen as a way of further engaging people in their own care. This was particularly evident in the study by Phillips et al. (2014). The focus of this study was on understanding the multiple perspectives of carers, patients and clinicians in enacting the

patient-as-professional role in the context of people living with chronic illnesses (Phillips et al., 2014). This study may be an exemplification of recognising the patients' own agency where the quality of the patient–clinician relationship was identified as the key essential element for enabling the patient-as-professional role.

Across the studies reviewed, patients identified a range of clinicians' behaviours as enabling them to feel empowered in caring for their own illness. These included finding common ground, informing, and providing clear results. It also included taking patient preference into account, as well as acknowledging and prompting patients' expertise (Hudon et al., 2013), and informing and involving patients' in their own care decisions (Sutanto et al., 2013). As the following quote illustrates, explicitly acknowledging the patients' agency was experienced as enabling and empowering: "He knows I can understand. . . occasionally, he says: 'Now, you know what to do, it's up to you, it's your responsibility, go ahead'" (Hudon et al., 2013, p. 5). When the relationship was valued and the patients' agency was respected, patients were more likely to follow the treatment prescribed for them: "The advice she's going to give me, for sure I will take it cause I know it will work" (Hudon et al., 2013, p. 5). In one of the studies reviewed, the authors proposed that "medication adherence was a way of demonstrating their (patients') appreciation towards their treating clinicians" (Sutanto et al., 2013, p. 1762).

3.3.2.4 Summary of enablers/positive encounters

To summarise, although positive encounters appeared less common, when they did occur they were overwhelmingly characterised by the quality of the therapeutic relationship where patients felt acknowledged as a person first. These encounters appeared more common with clinicians who were relationship focused. Some studies spoke of specific skills, such as effective communication and empathy, and others were more concerned with a general way of being, and the orientation of the clinician towards providing support to the person who is suffering.

Positive encounters were grouped under three themes. The first theme was concerned with the ability of the clinician to interact with the patient as a person with a history and a full life, as well as acknowledging the impact of the illness on that life. The second theme was concerned with the experience of being seen as an individual and perceiving the care as individualised to them. The third theme was concerned with patients feeling that their own expertise and agency in caring for their own illness was respected. Under this theme, certain behaviours by clinicians were identified as facilitating patients' own ability to care for their own illness.

3.4 Overall summary of Part 1: Care experiences of people suffering from chronic conditions

From the studies reviewed, patients' experiences appear to be shaped to a large degree by the clinicians' orientation towards their illness and their symptoms. Patients may experience clinicians who come across as more concerned with treating symptoms and illness, as being only interested in them to the extent to which it is directly relevant to the illness they are treating. Therefore, if the illness they are treating is hard to diagnose or non-diagnosable, some of the studies suggested that the person may feel as if they are some sort of an irritant (Håkanson et al., 2010; Thorne et al., 2000; Werner & Malterud, 2003). The literature reviewed indicated that these experiences may lead to a feeling of powerlessness and hopelessness on behalf of the person with the illness, and may have implications for the extent to which patients follow recommendations.

Clinicians who were perceived to demonstrate a primary concern for the person, and their relationships with them, appeared able to create relationships with patients, as persons, where patients felt supported, encouraged, and trusted to take an active role in caring for themselves. Further, through this focus on the relationship with the person with the illness, the findings suggest that patients may be more likely to follow through and act on their clinicians' clinical advice.

3.5 What about the clinicians' view of disease aetiology?

As outlined in the previous chapter, Descartes' thinking and Cartesian dualism still underpin how Western medicine views illness and disease by "privileging the observable" (Anjum, 2016; Borrell-Carrió et al., 2004; Broom, 2007; Crowley-Matoka et al., 2009; Damasio, 2001). The review findings presented above support this (Ali et al., 2014; Håkanson et al., 2010; Hudon et al., 2013; Koch et al., 2015; Sutanto et al., 2013; Thorne et al., 2000). In line with this doctoral research's orientation, I specifically attempted to explore, in reviewing the studies, the extent to which the authors attempted to interpret or make sense of their findings with reference to clinicians' view of disease aetiology and in the context of a broader biomedical context. Accordingly, in this section, I specifically focus on the extent to which the clinicians' worldview of disease aetiology was examined by the researchers in their interpretation of the reported care experiences.

Clinicians' perspectives on this matter were not mentioned or examined by most of the articles reviewed, which in itself perhaps is not too surprising, given that the included

studies were prioritising patients' care experiences, and therefore clinicians' perspectives were mostly inferred. However, attending to clinicians' beliefs in some of the research which examined the experience of people with hard-to-diagnose conditions such as lupus (Sutanto et al., 2013), multiple and complex chronic conditions (Koch et al., 2015; Tarrant et al., 2015) and chronic Lyme disease (Ali et al., 2014) could have deepened the insights gained.

For example, Ali et al. (2014) described patients' experiences of dismissive attitudes by medical professionals towards the "unexplained" or "undiagnosed" symptoms associated with chronic Lyme disease. However, Ali et al. (2014) did not explicitly relate these observations to dualism and its impact on clinicians' views of disease aetiology and subsequent approach when treating "undiagnosable" illnesses. As outlined in the previous chapter, the implicit dualistic assumption within the biomedical community may orient the clinician differently towards a person presenting with unexplained symptoms, which could have helped explain the variable care experience their participants received. Perhaps, if Ali et al. (2014) explored this dimension, it may have helped explain those positive experiences, where patients felt listened to and taken seriously. Similarly, despite acknowledging how some participants spoke of their experiences of feeling trivialised because their lupus symptoms were not well understood, Sutanto et al. (2013) did not connect these experiences to the dualistic epistemology governing medical training, which similarly may be of relevance in interpreting these results. By explicitly attending to the extent physicians held these views, it could have been possible to explore an additional interpretation of the reported variability of the care experiences.

Conversely, the possible impact of patients' view of the aetiology of their own illness and the impact that may have on the ways they perceive the clinical encounter was not examined either. In the Tunisian study for example, Tlili et al. (2015) reported how the participants had their own explanations with respect to the aetiology of their illnesses. These were connected to the modern unhealthy lifestyle and the nature of modern life. Participants spoke of stresses and strains and linked these to changes of the character of the times. They also spoke of their belief in a higher being causing this, and psychological stressors as triggers. However, Tlili et al. (2015) did not relate back to these views nor did they address how such views might relate to their observation that patients reported ongoing reliance on traditional medicine, despite the biomedical clinicians' dismissive attitudes towards it.

In the articles where clinicians' worldviews of disease aetiology were discussed, it enhanced and enriched the discussion of the findings. Håkanson et al. (2010), for example, explicitly discussed how the traditional dualistic perspective in modern healthcare made it difficult to understand the existential meanings of illness. And although Cocksedge et al. (2011) did not explicitly discuss dualism, they did acknowledge, at the outset of their article, how, in the context of biomedical training, the focus of teaching was aimed at the doctor's role in revealing organised pathology. Cocksedge et al. (2011) suggested that when it comes to the care for people with multiple chronic conditions, this orientation might be unhelpful in the management of many patients. Furthermore, the authors explicitly acknowledged how the education of medical students to take a biomedical and organic, diagnosis and treatment approach contrasts with the patient-centred orientation of sharing control in interactions, and taking account of patients' perspectives, which appear to require a mutual investment on behalf of both patient and doctor.

3.6 Critique of methodologies and methods used

The secondary purpose for this review was to examine what methodological approaches and methods have been used in qualitative research in this area, as well as to examine the kinds of understandings and insights generated by using such approaches. The aim here was to inform and scaffold methodological decisions, method selection and overall design for the present study. Accordingly, this section will cover:

- Methodological observations and critique.
- Implications for this doctoral research.

3.6.1 Credibility and fidelity of findings

Sandelowski (1993) argued that good qualitative research should exemplify the essence of a phenomenon, and Tracy (2010) suggested that credible qualitative research should explicate tacit knowledge through "thick" descriptions. Thick descriptions, a term coined by anthropologist Clifford Geertz and widely adopted by qualitative researchers, are in-depth illustrations that provide abundant and concrete details of contexts and experiences, where the authors illuminate their interpretations and descriptions with direct quotes that bring them to life. These are seen as one of the most important aspects of achieving credibility in qualitative research as they have the capacity to render the findings trustworthy and plausible. Tracy (2010) argued that good qualitative research

has the capacity to explore what is implicit and assumed, and shed light on what happens beyond the surface.

All of the studies reviewed provided quotes as illustrations of themes and to substantiate findings. However, although illustrative and helpful, in some instances they were more likely to be used as a justification for the theme or code constructed, but could not be construed as offering an in-depth illustration of patients' experiences. For example, Hudon et al. (2013) offered a multitude of quotes to substantiate their coding approach; however, there was no attempt to explore the tacit behaviours which may constitute what they referred to as the "enabling attitudes" of family physicians, and the descriptions could be described as only skimming the surface.

A few of the articles reviewed produced rich and thick findings which explicated and crystallised the tacit aspects of patients' experiences. The insights generated in these studies were logical and coherent and provided in-depth analytical explanation of what was going on in terms of the care experiences of patients (Håkanson et al., 2010; Tlili et al., 2015; Thorne et al., 2000; Thorne et al., 2005; Werner & Malterud., 2003). The verisimilitude of their descriptions indeed felt trustworthy, to the extent that a reader might wish to act and make decisions upon them.

Håkanson et al. (2010) investigated the experiences of care by persons with IBS with what was an admittedly small group of participants (nine patients), yet their study offered plausible and rich descriptions of the care encounter. They constructed themes that provided the reader with an appreciation of the experience of living with IBS, as well as an in-depth examination of the impact and consequences of the care encounters they had experienced. Interestingly, these authors were among the few who explicitly related their findings to the impact of clinicians' dualistic worldview on the experience of care. Likewise, in Werner and Malterud's (2003) study, which explored how women who suffer from medically unexplained conditions "worked" to appear credible as patients, so that they would be taken seriously by treating clinicians, thick descriptions crystallised and enunciated the lengths and efforts these women had gone to.

As a reader, those studies in which the researchers attempted to provide thick, credible and illustrative descriptions, indeed resonated with me long after I had reviewed them. These thick, detailed, concrete and life-like descriptions by a hand-full of the studies highlighted the care that is required in producing such reports.

3.6.2 Rigour

Sandelowski (1993) has argued that in the context of qualitative research, “Rigour is less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work” (p. 2). She suggested that trustworthiness in this context is achieved by making the research practice and process visible and therefore auditable. This is echoed by Malterud (2001) who argued that researchers need to be systematic and explicit about the process and procedures they followed in the analytical process. In reading those studies which offered such systematic and explicit processes, such as Werner and Malterud (2003), and specifically McCormack et al. (2010), I felt able to trust their findings. This is in line with Tracy’s (2010) proposition that rigour is about utilising appropriate and abundant sampling approaches and methods for data collection and providing the reader with detailed explanations about the process of transforming the raw data into meaningful findings. She cautioned, however, that rigour in-and-of-itself does not guarantee the quality of the final research product. Indeed, Thorne (2006, 2008) cautioned against the use of overly restrictive coding as a way of demonstrating rigour, when this is done without attending to the possible limitation of such coding on the creativity of the analysis.

The challenge in achieving this delicate balance between explicitly articulating the detailed steps of the research and following strict guidelines, whilst retaining the creative aspects of qualitative research, was indeed evident in the studies reviewed here. Most of the studies could be described as trustworthy as they made the research practice and process visible and thus auditable. However, it does appear that where a strict coding approach was used, the findings were more limited in exploration and interpretation, and arguably left the reader with a sense of the researchers being “straitjacketed” in their explorations. The degree to which the researchers followed strict coding guidelines appeared to approximate a positivist approach and could even be argued to be inconsistent with the ethos of qualitative research (Sandelowski, 1993).

For example, the study by Morales-Asencio et al. (2014) focused on the illness trajectory model. They provided a rigorous description of their approach and, in their analysis, focused primarily on coding reliability and solving disagreement between coders. Despite (or perhaps because of) their efforts to communicate their “objective” approach with focusing on the strict coding approach following the principles set out by Taylor and Bodgan (1998, as cited in Morales-Asencio et al., 2014), they may have failed to explore some crucial aspects of their data. In this article, the authors pointed

out twice that, despite systematic efforts in their health system to encourage chronic patients to use primary care, doctors in acute hospital settings remained the most valued. However, the authors did not explore why that might be, and how to improve the credibility of other carers. A reader may be left wondering, why is it that despite all the efforts in their system to direct patients to community care, doctors in acute hospital setting remained the most valued by patients? However, their strict, model-based coding approach inhibited this kind of broader exploration. Indeed, perhaps the authors had confused validity with reliability by focusing on inter-coder reliability as a way of exemplifying the validity of their study (Sandelowski, 1993).

Furthermore, other authors who followed this route, such as Hudon et al. (2013), seemed to fall into many of the analytical traps identified by Thorne (2008, 2016), as well as Thorne and Darbyshire (2005) and Sandelowski (1986). Traps such as justifying claims in their findings by counting the frequency of mentions of a particular issue in their data, and not explaining how patients were selected in relation to their phenomenon of interest. Specifically, in Cocksedge et al. (2011), the analysis was limited to applying a pre-existing lens of a “holding” relationship – a doctor-patient relationship which is defined as the doctor’s ability to establish and maintain a trusting and reliable relationship which provides support for the patient, without expectation of the patient being cured. In their analysis, the quotes used seemed to be more reflective of this lens than the themes identified by the authors on the basis of the data. For example, in a theme named “judgement on the other”, the authors quoted a patient referring to their GP as, “He has been there for me every step of the way. You know he really is, I’ve just got to say he is my friend” (Cocksedge et al., 2011, p. 2488). The link between the theme and the quote selected seems tenuous. This quote appears more to allude to how the patient interviewed experienced the relationship in the context of the medical encounter as “friendship”. I propose that other aspects of the interview could have been interrogated for the subtle ways in which the GP had achieved this.

Indeed, these observations echo Tracy’s (2010) assertion that rigour does not guarantee quality, and that rigour goes beyond a systematic and explicit articulation of the research process and coding decisions. A single focus on any one aspect of rigour alone, and out of balance with other important aspects, appears to result in limited findings and leaves the reader dwelling on the surface of the experience. For example, in both reviews by Koch et al. (2015) and Sutanto et al. (2013), which utilise rigorously documented, systematic approaches, there is little attempt to explore underneath the

surface to understand the underlying mechanisms that may be at play for promoting greater communication among clinicians and with patients, other than providing access to electronic, integrated medical records. I do, however, acknowledge that this may be due to the limitations inherent in these methodologies, with their perceived focus on description rather than interpretation.

3.6.3 Reflexivity

Having read extensively about the importance of being reflexive as a qualitative researcher (see Introduction), it was surprising to discover that there were very few instances of researchers' reflexivity, even though all the research reviewed was qualitative. Further, there were hardly any instances of researchers identifying what their professional backgrounds were, and the ways in which that might impact on their analysis, even though their professional backgrounds did seem to influence the ways in which they interpreted their data.

For example, in Koch et al. (2015), some of the researchers' background was in evaluation, which could arguably explain their orientation towards electronic solutions. On the other hand, in those instances where background was accounted for and examined thoughtfully, the discussion and analysis that followed was helpful and thought-provoking. In their study of the experience of people with chronic Lyme disease, the researchers disclosed their professional backgrounds as family physician trainees and that one of them had a Complementary and Alternative Medicine background (CAM) (Ali et al., 2014). Their study was reported as being the first study to report frequent CAM use among Lyme patients, and that they did not expect patients to so openly report their use of CAM to the level they did. Ali et al. (2014) indeed hypothesised that because one of the researchers was CAM-trained, participants may have felt more able to discuss their use of CAM, whereas with conventional providers, patients often feel reluctant to discuss CAM use. However, I also suggest that by disclosing this background, the researchers may have unintentionally taken the participants down this particular route. Nonetheless, by being explicit about it, the reader was able to make his or her own judgement in this case.

This article specifically helped me in thinking through the extent to which I should disclose my own illness status to participants, and at which point and for what purpose. This also affirmed the importance of being cognisant throughout the research of the place and space for being reflexive in analysis and writing so that the reader is able to form their own views and reflections about the analysis.

3.6.4 Resonance

Consistent with my orientation towards influencing the practice of caring for people with chronic conditions, this quality criterion was selected because it directly speaks to the ability of research to affect the audience towards generalising and transferring the findings to other clinical contexts (Tracy, 2010). Otherwise known as the “so what” of research (Labaree, 2017), for me this is specifically concerned with research impact. Tracy (2010) sees resonance as being comprised of the aesthetic merit of the research product as well as the transferability and naturalistic generalisations that can be made of the findings. The former relates to the way the text is presented, which can have an emotional impact and encourage the reader to think and to feel - and perhaps change as a consequence. And the latter – naturalistic generalisations - are achieved when the reader can see and feel that the research has some overlap with their own circumstances and therefore can intuitively transfer it to their own practice context. Tracy (2010) suggested that readers are more likely to make choices that are based on their own intuitive understandings of the research when they are *shown* rather than *told* what to do.

Appreciation of aesthetic merit is, by definition, subjective. For me, the aesthetic merit related to credibility and the fidelity of the findings. Those studies which featured rich and nuanced descriptions, such as Werner and Malterud (2003), Håkanson et al. (2010) and Thorne et al., (2005), had an emotional resonance for myself as a reader and former patient and were closely related to my ability to make naturalistic generalisations as a consequence. In fact, I would argue that credibility is a necessary and perhaps even sufficient condition for resonance. Behavioural change is effort-full and I suggest that studies that advocate a change in behaviour which fail to resonate strongly with the reader through thick and nuanced descriptions may fail to effect that change.

Further, in assessing the studies’ resonance and reflecting on what might be needed to propel clinicians into reflecting on their practice, the approach taken by Thorne et al. (2005) and Werner and Malterud (2003), of offering reflections for practice rather than prescribing practice recommendations, resonated powerfully. The exploration by Thorne et al. (2005) of the impactful experience of “being seen” by patients did not conclude with a checklist, but an invitation for reflection. Likewise, the investigation by Tlili et al. (2015) of popular perspectives of everyday Tunisians on their biomedical treatment was able to invite exploration of practice by clinicians operating in this context by providing “thick” description that powerfully resonated, even while also

alluding to the difficulty encountered by patients who have a culturally different way of conceptualising their illness. They also highlighted the need for patients to feel recognised and for their voices to be heard, as an invitation for clinicians to self-reflect.

3.7 Methodological implications for this research

By examining the kinds of understandings and insights generated using those approaches, this review provided an important scaffold for the design of the present study in three distinct ways:

- Ongoing careful attention to documenting reflexivity practices.
- Ways to achieve thick descriptions and therefore credibility and resonance in the final product.
- Approach to sampling as it pertains to disease type.

3.7.1 Reflexivity practice

It was somewhat surprising to see how little reflexive discussion was evident in the articles reviewed, given that reflexivity is seen as a way of accounting for hidden skewness in qualitative findings (Malterud, 2001). Trustworthiness in qualitative science is said to be about being transparent and therefore auditable in the process of practising good science (Sandelowski, 1993).

For example, with little exception (e.g., Ali et al., 2014), there was no consideration of how researchers' professional backgrounds may have influenced their findings. Given the circumstances outlined in the introduction regarding my personal connection to the research topic, I had intended from the outset to be transparently reflexive. As a consequence of this review, I have come to understand the nuanced ways in which the omission of a disciplined and transparently reflexive practice can detract from the research findings, and how its inclusion can enhance overall quality and resonance. As a consequence, I have deliberately employed a multi-pronged approach to documenting and accounting for my personal experience, beliefs and perspectives, from the outset, throughout the data collection and in the analysis process, which is outlined in detail in Chapter 5.

3.7.2 Thick descriptions, credibility and resonance

The methodological review process has highlighted the subtle but important difference between the superficial use of data to support pre-existing themes (see, for example,

Cocksedge et al. (2011)) and those studies where thick descriptions were used which resonated and resulted in deep reflection for me as a reader. Consequently, I have become aware and mindful of the art of qualitative analysis and writing, and the need for careful and deliberate focus on evoking those vivid, detailed and concrete descriptions so that the findings are seen as trustworthy and credible (Tracy, 2010).

3.7.3 Approach to sampling as it pertains to disease type

The mix of diseases and conditions studied has led me to reflect on the value in focusing qualitative research of patients' experiences on people with a single condition, or more broadly, given that the WPTA is practised by clinicians from many professional backgrounds and with people with a wide range of chronic illnesses. An argument could be made for focusing on a specific illness and a specific clinical orientation. However, this review illustrated that the findings regarding the care experiences of people with chronic illnesses were quite consistent, despite the different types of chronic conditions and illnesses studied (including, but not limited to, lupus, Lyme disease, asthma, osteoporosis/arthritis and non-specified chronic conditions), different clinical disciplines of treating clinicians (family physicians, nurses, specialists), and the different countries, languages and cultural contexts (UK, Canada, USA, Spain, Nordic countries, Australia and Tunisia). Therefore, this observation was helpful in considering the merit of studying the experience of people who suffer from a wide range of chronic conditions/illnesses in the present study without limiting to a specific illness type or specific discipline of the WPTA treating clinician. The specific and detailed approach to sampling is discussed in depth in Chapter 5.

3.8 Conclusion

This chapter outlined how qualitative research exploring the treatment experience of people who suffer from chronic conditions supports the assertions made in Chapter 2 about the potential impact of dualism and EBM-based treatment protocols on the patient's experience. This review also illustrated the multiple ways in which people with chronic conditions often endure difficult experiences when being treated for their conditions.

In conducting this review, an overarching knowledge gap has emerged. Most of the research into the experience of care by people with chronic conditions does not explicitly and transparently tackle the impact of clinicians' views of illness aetiology on the experience of care by patients. This is despite ongoing research projects consistently

identifying that the experiences of people with complex multi-morbidity or with symptoms that have no diagnosable aetiology are more negative than those who have a single morbidity with clear aetiology. Dualistic assumptions about disease aetiology seem to influence the care experiences of people who suffer from chronic conditions. And yet, most existing research rarely explicitly examines the role these assumptions play in the care experience. Therefore, exploring the experiences of people, treated for their chronic conditions by medical professionals who hold a non-dualistic view of illness aetiology, may provide insights that could help improve these experiences.

This study intends to consider the experiences of people who suffer from chronic conditions and who were treated by WPTA clinicians. It is hoped that this research will inform the practical application of this model. It is also proposed that this research could have the capacity to inform more broadly the clinical care approaches for chronic conditions. Accordingly, the present research asks the following question:

What can be learned from an in-depth consideration of the experience of persons, treated in the non-dualistic WPTA for their chronic conditions, that could be of general relevance to improving the mainstream care approach of chronic conditions?

Chapter 4: Methodology

This chapter discusses the methodology utilised in the present study – Interpretive Description. I will outline the methodological considerations which guided my decision-making and the rationale for eventual selection of Interpretive Description as the methodology for undertaking the study.

4.1 Where do I start? Methodological considerations

Qualitative methodology was chosen for this project because of its core aim to understand the subjective experience of patients to inform clinical practice. Qualitative inquiry acknowledges that the researcher is, in fact, part of the research project. Sandelowski (1986), for example, suggests that a way of enhancing the credibility of the qualitative enquiry project is for researchers/investigators to describe and interpret their own experiences, and behaviour, in relation to those of their participants. This is because a major threat to the credibility of a qualitative study emerges from the closeness of the investigator-participant relationships. In the case of this particular doctoral research, this closeness may be amplified because of my health and particularly illness, and my own experiences with WPTA.

Given the original aim of the study, I read widely in the fields of methodological philosophy and qualitative research in healthcare to inform my thinking. In considering which methodology would be best suited for my research, I also sought input from four medical practitioners. They all practised the WPTA and their perspective helped me to ensure I chose a method that would facilitate the aim of influencing clinical practice. Further expansion of the approach to consultation is available in Chapter 5, and a detailed summary of the process is available in Appendix A.

Initially, I found the process of comprehending that ontological and epistemological assumptions are integral to, and should inform, all methodological aspects of a research project, difficult (Byrne-Armstrong, Higgs, & Horsfall, 2001). This may have been exacerbated by the phenomenon of interest, WPTA, also being conceptually complex as well as arguably controversial. Adding to this sense of complexity was the explicit aim of producing a research product that could inform clinical practice more broadly within the existing biomedical paradigm with its positivist bias.

A further difficulty in selecting a methodology was the sense that some methodologies commonly adopted in qualitative health research appeared, at times, to take centre stage in research projects, and appear to “shove” the actual research question to the side. This has been called “Methodolatry” (Chamberlain, 2000), a preoccupation with method as opposed to substance. My own closeness to the phenomenon being researched contributed to the complexity. From the very beginning, I was mindful of my desire to design a study and select a methodology, which would privilege participants’ perspectives over my own (Underwood et al., 2010).

It was reassuring to find that I was not alone in my struggle to negotiate the “research convention of a single methodology in the face of the everyday experience of multiple methodologies” (Byrne-Armstrong et al., 2001, p. 5). An edited book examining the lived experience of those commencing qualitative research (Byrne-Armstrong et al., 2001) provided a needed perspective. It was reassuring to read that other neophyte researchers, trying to fit within a convention of “one methodology to rule them all”, had experienced a feeling of bewilderment, loss and confusion. This book provided reassurance that in research methodology, methods can often emerge and transform as knowledge is produced throughout the research process while retaining their methodological coherence. In addition, the trend towards diversification of a variety of models and explanatory approaches for detailed problems (Flick, 2006), gave me the confidence to critically evaluate the appropriateness of a range of methods and methodologies for my specific planned research.

To inform my methodological choices, I compiled a table in which I critically evaluated a number of candidate methodologies. These methodologies were chosen as candidate methodologies following discussions with my supervisors, other health researchers and attending a qualitative methodology master class offered in my university. They were selected as possibilities because they were seen as potentially appropriate in answering the research question.

In trying to find an appropriate methodology, I considered the following:

- Pluralistic orientation towards qualitative methodology (Chamberlain, Cain, Sheridan, & Dupuis, 2011; Creswell, 2007), and including thematic analysis (Braun & Clarke, 2006) as a key method for data analysis;
- Interpretive Description (ID) (Thorne, 2008; Thorne et al., 1997; Thorne et al., 2004);

- Phenomenology (Carel, 2012; Crotty, 1998; Gergel, 2012);
- Narrative study (Creswell, Hanson, Clark Plano, & Morales, 2007; Willig & Stainton-Rogers, 2013); and
- Case study research (Creswell et al., 2007).

For further details of the strengths and limitations of these methodologies as they related to my research aims, see Appendix B. I constructed a number of tables in assessing the methodologies; the table presented in Appendix B presents the final summary of this process. Initially, I also considered using other methodologies such as grounded theory (Charmaz, 2006), Narrative Psychology (Hiles & Čermák, 2013) and Interpretive Phenomenological Analysis (Eatough & Smith, 2013). However, I discarded them at an early stage because they seemed to impose a frame on the analysis that was not in keeping with my practice intention. As such, they are not included in Appendix B. Rather, the methodologies listed above and compared in Appendix B are the short list of methodologies which were considered in more depth as being potentially appropriate to my research question and intended purpose. I described my wrestling with methodological choices during the second positionality interview undertaken in August 2015, after I was formally accepted into the doctoral programme. In replying to the interviewer questions about my methodological choices, I attempted to articulate my thinking at that time:

...the phenomenological kind of framing made sense initially because it is like how do patients apprehend it and how do they comprehend it? That kind of made sense in that context. So I started reading about phenomenology and also one of my supervisors was exposed to grounded theory so I started reading about that as well. And none of these methodologies were in line with what I had a sense of what I was wanting to achieve, the purpose of me undertaking this.
(Second positionality interview, August, 2015)

In considering the different methodologies, I attempted to clarify the links between methodologies and epistemology, how each methodological choice would allow or preclude possible research questions, and if so, what would be the sampling and data collections implications. I also evaluated each methodology for the degree to which there is a structure imposed on the analysis. My key take-out of this process was the importance of being very cognisant and mindful that the methodology I chose would be consistent with my intended central aim for the research to influence practice.

From the outset, I was drawn to Interpretive Description and Sally Thorne's writing because the research produced using that methodology seemed to address all of my concerns. However, the following memo I wrote in November 22nd, 2014 illustrates my initial reluctance to adopt this methodology despite its apparent appropriateness:

My key concern is that it seems to be very focused towards nursing research and knowledge which raises the question of how I could use it. Perhaps focus on using the principles from it. Also values the use of clinical nursing knowledge which I might be able to adopt from the perspective of the patient?

The explicit orientation of Interpretive Description within the nursing profession seemed to me at first as rendering this methodology inappropriate for me. It is interesting to reflect how locating a methodology within specific disciplinary boundaries (i.e., nursing), may lead to low uptake by researchers from other disciplines. Initially, I was prepared to adapt different qualitative methods such as thematic analysis (Braun & Clarke, 2006) and constantly justify my methodological choices. However, throughout this initial reading phase, I kept going back to reading both the methodological writing on Interpretive Description, as well as health research articles reporting on Interpretive Descriptive studies. Those readings resonated with me and appeared congruent with what I sought to achieve in my own research - an insightful and thoughtful piece of research on a clinical phenomenon, capable of informing clinical practice.

Further, it became clear that Interpretive Description can be, and is, used by researchers from other professional backgrounds. For example, Hunt (2009) studied the moral experience of health professionals in humanitarian work. After further investigation, I came to understand that in Interpretive Description, professional background is brought to the foreground and its influence on the research product is explicitly acknowledged. The importance of acknowledging professional identity as part of the theoretical fore-structure for one's research is powerfully illustrated by Thorne, Paterson, Acorn, et al. (2002). They found in their meta-analysis of qualitative research on chronic illness experiences, that the disciplines of researchers shaped their study even when the same *methodology* was adopted. They described how they detected important patterns in the way research problems were framed, research questions were posed, data were gathered and analysed, and findings were interpreted. What they found was that:

- psychologists were primarily oriented toward psychological implications and processes associated with chronic illness;
- sociologists were focused on the implications of common social or cultural rules and structures associated with illness on patients' behaviour; and
- anthropologists tended to locate the patterns they documented regarding beliefs about health and illness within the larger social and cultural context and within organisational frameworks.

Thorne, Paterson, Acorn, et al. (2002) commented that although the methodologies, language, methods, and questions used, might appear on the surface to represent similar kinds of inquiry, the actual research reports were often strongly shaped by what the researcher believed to be the point of gaining new knowledge from their own disciplinary perspective. This observation resonated for me, as it has been my own observation that professional identities shape so much of how we see the world.

Following the reiterative and reflexive process of thinking through what mattered most when selecting a methodology and with the support of my supervisory team, I settled in April 2015 on the guiding principles of the Interpretive Description methodology (Thorne, 2008) as the most appropriate, congruent and consistent approach to guide the research design and method selection for this study.

4.2 Interpretive Description (ID)

ID is a methodology that was designed to enable small-scale qualitative investigation of a clinical phenomenon. This methodology was designed specifically for the purpose of identifying themes and patterns, within the subjective perceptions of persons who experience illness, which are capable of informing clinical understanding (Thorne et al., 2004). The reason why ID was developed was to influence clinical practice. This is done through generating research that focuses on individual subjective experience. ID explicitly acknowledges that, under this methodology, research outcomes would constitute a “tentative truth claim” about the commonality within a given clinical phenomenon. One of the important tenets of ID is the way by which this tentative truth is to be communicated in the research report. The challenge is to make such tentative truths accessible to health professionals, extending their insight for practice and contributing to the collective effort of sense-making in the context of the variable and eccentric reality of health application (Thorne et al., 2004).

ID aims to influence practice rather than theorising, in contrast to some approaches such as grounded theory (Thorne, 2008). It offers a way to rigorously generate new understandings and knowledge about the highly experiential, individualised and implicit aspects of the human health experience. The goal of an ID research report is to offer a nuanced understanding of health experiences, to help guide real practice decisions that would be made by clinicians (Thorne, 2008). This orientation was judged consistent, congruent and coherent with the original purpose of undertaking the planned research, which is to generate knowledge that may influence recommendations for practice for clinicians who care for people with chronic illness.

In addition, ID calls for method flexibility to ensure the best instruments and approaches are used to gather the data required to influence practice. Thorne et al. (1997), in their first article on ID methodology, cautioned researchers against being set in their methodological ways, and urged them be open to methodological flexibility when necessary. This orientation of ID towards method flexibility also addressed my concern of the potential for being caught in the methodolatry trap.

However, in my initial reading of Thorne et al. (1997) and Thorne (2008), I was not clear on how to select individual methods appropriate to the research question, whilst ensuring they remained congruent with the overall methodology. Being able to attend a workshop run by Sally Thorne herself, where some of the practical applications became more explicit and tangible, helped resolve this issue. Nonetheless, for other researchers not in a position to attend this workshop, this aspect of ID may still present a challenge.

Further, ID is not sufficiently explicit in identifying what specific methods it borrowed from other methodologies and the justification for doing so (Hunt, 2009). Therefore, the onus is on the individual researcher to be transparent and thoughtful about the use of the various methods so that they remain congruent with ID, something of a hefty challenge for a neophyte researcher. For example, although researchers can consult grounded theory texts to further understand the use of sensitising concepts in an ID study (Charmaz, 2006), they may not understand that borrowing another aspect of grounded theory, such as how to initiate line-by-line coding, may not be congruent with ID's orientation of asking broad questions of the data (Hunt, 2009). An additional challenge with the use of this relatively new methodology, in the context of existing well used and respected qualitative methodologies in health research (Malterud, 2001), is the need for its use to be well justified. By opting not to use existing methodologies with their

demonstrated history of research expertise, I had to comprehensively justify why I opted for ID and not, for example, phenomenology or narrative research.

4.2.1 The theoretical fore-structure of this study

Under this methodology, the researcher is advised to locate:

- their theoretical allegiances on entering the study,
- themselves within a discipline, and
- their personal relationship to the ideas they hold.

4.2.2 Locating theoretical allegiances

Theoretical positioning is seen as relevant to the extent it helps with the research task (Thorne, 2008). For example, in a study undertaken for the purpose of understanding the intention underlying the actions of men choosing not to access cancer rehabilitation services, the researchers followed ID guidance and used Symbolic Interactionism as the framework to make it possible for them to explore the meaning in the actions of their study participants (Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2014).

In thinking about locating theoretical allegiances, I found that D'Cruz (2001) account of her PhD research provided a cautionary tale of the issues that might arise from selecting theoretical allegiances too early in a research project focused on influencing practice. Initially, D'Cruz (2001) described being captivated by the critical philosophy of Foucault in particular and later on by Bourdieu's theory of practice. She came to describe her orientation as "fractured constructionism" (D'Cruz, 2001, p. 22). But as she applied it to her own research and engaged more deeply in the associated concepts of epistemological and ethical relativism, she became more aware of, and concerned about, the ethical implications in the context of the real life setting of her research. She discovered that her theoretical orientation of "fractured constructionism" created ethical discomfort in her work with children with real injuries and real tragedies. D'Cruz (2001) felt that in her own research, through the risk of over intellectualising, she was bordering on dismissing the very real daily concerns of her colleagues and, most alarmingly, the lived experiences of children she worked with. Nonetheless, she described how she still mindfully retained this fractured lens, while attending in practice to the reality of the people she was working with.

This perspective resonated with me in the context of undertaking applied research with the intent and purpose of influencing practice. In the context of ID, the researcher is

asked to reflect on how a theoretical perspective can best inform the design and analysis of one's specific research, of a specific health phenomenon. At the early stages of my research, other than being committed to a non-dualistic theoretical underpinning, I did not have a specific theory that I thought should inform my design and analysis. I intended to remain open and inquisitive as to the possibility that a specific theoretical perspective might become relevant for design and/or subsequent analysis as I progressed through my research. Accordingly, I documented the progress and shifts in my thinking to the point such a perspective may arise.

In the absence of a specific theoretical perspective, I initially approached my research from the broad philosophical assumptions of constructionist epistemology (Crotty, 1998) which is consistent with ID (Thorne, 2008). Drawing on this epistemology, the key philosophical assumptions underpinning my research were that:

- Reality is complex, contextual, constructed and inter-subjective;
- The inquirer and the “object” of inquiry interact to influence one another – the knower and known are inseparable;
- There are multiple, constructed realities that can be studied only holistically; and
- No *a priori* theory could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data (Crotty, 1998; Thorne, 2008).

4.2.3 Locating within a discipline

Thorne (2008) argues that each discipline has what it considers to be the “burning question” around which the scholarly community within that discipline gathers. ID advocates that researchers not only articulate their disciplinary stance, but also reflexively and explicitly position their research within it. My professional foregrounding is that of an executive mentor and coach who was trained in psychology and strategic consulting. I draw on this background and on the principles of positive psychology to mentor and coach executives and founders of businesses who face complex challenges in their work and lives. In my work, I am oriented towards how people can become agents of their own circumstances, take accountability and responsibility for their actions, and what it is about their interactions with others that helps and inhibits that. I am clear that my professional identity and attitudes towards behavioural change influenced the practice orientation of the research question.

4.2.4 Locating personal relationships

For the proposed study, the aspect of locating personal relationships as part of the theoretical fore-structure is of utmost importance and therefore was addressed in detail in Chapter 1, as well as Chapter 5 and in the discussion in Chapter 8.

4.3 Summary

Within this chapter, I outlined the methodological considerations undertaken in the process of selecting a methodology for this research. Following a process of considering five commonly used qualitative health methodologies and reflecting on their appropriateness for guiding the present study, I selected ID as the guiding methodology for the present research. This chapter provided a summary of ID, and outlined my theoretical allegiances at the outset of the research as well as my professional allegiances. In Chapter 5, the research design is described and the methods used are detailed.

Chapter 5: The research design and methods used

Within this chapter, I outline the research design, which essentially consisted of five steps: preliminary work, secondary analysis, the first phase of the primary study, the second phase of the primary study, and construction of a findings vignette. I also provide a detailed overview of the reflexive approach undertaken throughout the research process. Consistent with ID, the research steps were designed to help achieve the original intention of generating meaningful recommendations for mainstream therapeutic practice.

The first step consisted of preliminary work, consulting with WPTA practitioners to inform the design of the research. In addition, as part of the preliminary stage, a pre-pilot interview was conducted. These processes are discussed in detail below.

In Step 2, I undertook secondary analysis of two existing data sets from previous unrelated studies consisting of interviews undertaken with people treated by the WPTA. This was done for the purpose of scaffolding the primary research design, recruitment and analysis. The first phase of the primary study was undertaken in Step 3. This consisted of interviews with participants who were treated by WPTA clinicians in an immunology department in a hospital setting. The second phase of the primary study was undertaken in Step 4. This consisted of interviews with participants who were treated by WPTA physiotherapists in two different clinics. The approach taken to sampling, recruitment and data collection in the primary study are detailed below. Given my personal connection to the topic of this study, outlined in detail in Chapter 1, the reflexive approach undertaken to documenting positionality throughout the research process is also described in detail.

The process utilised to analyse the data in Step 4 is outlined in detail. This includes the approach utilised for coding and memo generation, which included an explicit reflexive practice. The fifth and final step concerned the construction of a vignette as a way of orienting the reader towards the findings.

I conclude the chapter highlighting aspects of this research that were used to enhance its quality. These included reflexive practices, steps undertaken to enhance analytic rigour, and writing approaches to strengthen findings' credibility, fidelity and resonance.

5.1 Step 1: Preliminary work

Prior to undertaking the research itself, some pre-work to further help frame and ground the research design was necessary. This was deemed important firstly because of my personal closeness to the topic (see Chapter 1 for details). Secondly, as a mature but neophyte researcher, returning to academia after a significant gap, undertaking pre-work to further hone my academic interviewing skills was seen as cautious and respectful, prior to approaching patients to be interviewed. Thirdly, and perhaps most importantly, gaining practitioners' perspectives at the outset was deemed relevant, given the ultimate aim of influencing practice. Therefore, it was decided that a consultation with practising WPTA practitioners would be a helpful way to canvass some of these issues. In addition, a pre-pilot interview with me as the interviewee, interviewed by one of my supervisors, was seen as a potentially beneficial way of testing the proposed interview format.

5.1.1 Consultation with clinicians

Consultation was undertaken for the purpose of:

- gaining perspectives on guiding the research design so that research will be conducted in an ethical and respectful manner;
- exploring the ways that a reflexive practice on my part could enhance the trustworthiness of the research product in their eyes;
- exploring their thoughts on the practical as well as theoretical approaches to guide the sampling process; and
- exploring and gaining insights as to possible data gathering approaches which would generate rich and thick findings which would guide practice.

Six clinicians who practise WPTA, from both private and public practices, were consulted. Past and current conveners of the MindBody diploma nominated these clinicians as experienced and reflective practitioners, representing the different disciplines that practise WPTA and who also have some understanding of qualitative research. They included a registered medical immunologist, a registered medical rheumatologist, a medical general practitioner and three psychotherapists from the North and the South Island of New Zealand. For more details of the consultation process, see Appendix A.

5.1.2 Implication for the research

The consultation informed a number of key design decisions. First, most of the private psychotherapists felt that people primarily sought their help for “psychologically related reasons” rather than for “physical illness”. Given the focus of this doctoral study on the care experiences of persons with chronic physical illnesses, recruitment and data collection via private psychotherapy WPTA clinicians was seen as unlikely to yield access to eligible participants. Interviews with the hospital based medical practitioners identified that in this context people were treated by the WPTA for chronic “physical conditions” consistent with the research question. I therefore focused on the immunology department as the starting point for recruitment in the primary study.

In addition, all of the clinicians consulted were explicit about how important it was for them that I demonstrate reflexivity throughout this doctoral research. They wanted to be able to ascertain for themselves the ways in which my own experiences influenced my findings and conclusions. As discussed in detail in Chapter 1, I explicitly included reflexive practice as a researcher from the outset of this project. ID offers methodological guidance on how researchers can explicitly identify their personal relationships to the research topic while still refraining from over-inscribing themselves into the data (Thorne, 2008). Furthermore, Sandelowski (1986) argues researchers in qualitative endeavours should leave a clear decision trail from the very beginning of their study, to the very end, so that any reader or researcher can follow the progression of decisions and understand the logic of the research. She explains it as being about describing the “what” and justifying the “why”.

Reflexivity was demonstrated in this project in three key ways. First, in Chapter 1, I identified and acknowledged my place and presence at the outset and explicitly articulated the preconceptions I brought (Malterud, 2001; Thorne & Darbyshire, 2005). Secondly, I attempted to critically examine throughout the research how these preconceptions, as well as other personal and professional factors, may have influenced how I approached the methods from sampling, through to how interviews and the analysis was undertaken (Underwood et al., 2010). I did that through conducting a pre-pilot interview with one of my supervisors who interviewed me using the proposed interview guide. I also conducted two positional interviews prior to commencing primary data collection and I used memoing throughout the analytical process. See Section 5.1.5 below on reflexivity practices undertaken for a full description.

5.1.3 Pre-pilot interview

As noted above, I undertook a pre-pilot interview as the “participant”, interviewed by one of my supervisors. This was for the purpose of identifying personal feelings which might arise through the process of being interviewed and developing a greater appreciation for the challenge of sharing very private experiences (Chenai, 2011). This also served as an additional way to explicitly document my pre-existing assumptions so that they could be recognised and challenged throughout the research process. See Appendix C for a summary of the pre-pilot interview. The interview was recorded but not transcribed fully. Appendix C includes the questions used in the pre-pilot as well as the summary comments I wrote following the interview. It also offers a sample of the reflexive notes written while listening to my interview.

5.1.4 Implications for the research

The pre-pilot interview further confirmed my own preconceptions (see Chapter 1 for details) about the topic and the need for disciplined, transparent reflexivity in the research. As a consequence of this interview, I became even more aware that I needed to mindfully construct an approach that would result in thoughtful implications for practice, which are based on the collective experiences of the people studied rather than my own (Thorne, 2008). Following this pre-pilot, I included two key design elements: a) a disciplined and continual approach to reflexivity through documenting my positionality throughout (see Section 5.1.5 below); and b) the use of secondary analysis of two existing and unrelated (to this study and to each other) qualitative data sets with people who underwent WPTA, to inform primary data collection. For a comprehensive explanation of why and how secondary analysis was used to manage the possible tension which may arise from myself as the primary research instrument, see Step 2 on secondary analysis below.

5.1.5 Reflexive practice through documenting my positionality

Two key methodological devices were used to continually document my own positionality in this research: positionality interviews prior to undertaking the interviews, and continuous memoing during the interviewing process and the analysis.

As outlined in detail in Chapter 1, I undertook two positionality interviews prior to commencing the data collection phase. The first was done prior to commencing the doctoral journey on 13 May, 2014 with a hermeneutic researcher not connected to this

study. I personally transcribed this interview and documented my reaction to the initial telling of my story. See Appendix D for an extract from this positionality interview.

The second positionality interview was done a year later, following the completion of the requirements to be confirmed as a PhD candidate and prior to undertaking the secondary analysis on 18 August 2015, with a different researcher as an additional checking-in point. See Appendix E for an extract from this positionality interview. I personally transcribed this interview.

I drew on both interviews in writing the introduction and personal postscript for this research. Both interviews also informed the initial interview guide. Most importantly, through conducting these interviews, I was able to reflexively document my assumptions going into this research (see Chapter 1, Section 1.3) and these assumptions were then used as sensitising concepts throughout the analysis. I chose not to include the data from these interviews as part of the analytic process in keeping with my intent of exploring other people's experiences of the WPTA.

Finally, the continuous memoing process is outlined in more detail in relation to the primary study in Steps 3 and 4 below. Continuous memoing enabled me to explicitly document my own intellectual and emotional reactions to each interview analysed, from the secondary analysis onwards. I did so on an ongoing basis throughout the research. I used these memos extensively throughout the analytical process and in the writing stages of the research.

5.2 Step 2: Secondary data analysis

As outlined above in Section 5.1.5, the consultation highlighted the degree to which clinicians were mindful and even cautious of my closeness to the research topic and how that might influence the findings. As outlined in Section 5.1.5 above, one way of addressing this was embedding a reflexive process throughout. Consistent with ID, another approach identified that could possibly address some of these concerns is the use of secondary analysis of other researchers' data. Furthermore, according to ID, secondary analysis can also become part of the scaffolding process for a planned study.

Qualitative researchers are increasingly advocating the use of secondary data concerned with research questions similar to one's own (Heaton, 2004; Thorne, 1998, 2008), as such analysis can help frame and fine-tune the eventual process of primary data collection. Further, undertaking secondary analysis can enhance the representative

credibility of findings generated, as the use of multiple data sources, including data gathered by other researchers, can be a useful way of obtaining knowledge that goes beyond the single angle of vision of any one researcher (Thorne, 2008).

Secondary analysis is seen as helpful in addressing some of the limitations which arise from the reliance on the researcher as the primary instrument for data collection (Thorne, 2008). For example, a salient feature of the data, obvious to the original researcher, may not be obvious to the secondary researcher who is one step removed from the data. As a consequence, the secondary researcher may be able to see things which might have been obscured for the original researcher (Thorne, 1998). It is also seen as a respectful way of treating the time participants have invested in any given qualitative research project by using their words to help inform, and further, subsequent academic research in aligned areas (Thorne, Paterson, Russell, & Schultz, 2002). Lastly, most researchers are well aware their own primary analysis could only capture so much of the context of the phenomenon they studied (Thorne, 2008), and multiple interactions through “different eyes” with the same data set are likely to generate new insights (Sandelowski, 2011).

In the context of this doctoral study, secondary analysis was also seen as a potentially constructive way of handling my emotional closeness to the research topic. By undertaking the secondary analysis, I was able to work through my own emotional reactions while listening to the illness stories of other people. Although difficult to begin with, through the memoing process (see below) and talking to a psychotherapist not related to this study, I was able to work through these difficulties. Further, when the time came and I conducted my own interviews, I found that I was able to attend fully to the people in front of me, without jeopardising my own health and wellbeing.

In summary, the key reasons for undertaking secondary analysis in the context of this research included:

- a) Drawing on what knowledge already exists to scaffold the current research, an approach consistent with ID;
- b) Informing key methodological decisions including sampling approach and interview structure for the primary study; and
- c) Exploring my own emotional response and developing strategies to manage this in the primary study.

5.2.1 Choosing data sources

Little academic research has been done on the WPTA. Most of the articles and books written on the topic were written from the clinicians' perspective; see, for example, Broom (1997), Broom (2007) and Broom and Joyce (2013). In the planning and design stage of this research, I became aware, through the expert clinicians I consulted, of the existence of two qualitative data sets. These clinicians suggested that the data sets could provide insights into the patients' perspective of being treated by this approach. In the consulted clinicians' view, both sets provided potentially good insights into the care experience. According to these clinicians, analysing these data sets was seen as a potentially helpful process to further scaffold the study.

5.2.2 Data sources description

Source 1: Treating chronic spontaneous urticaria using a brief whole person treatment approach. A proof-of-concept study (Lindsay et al., 2015)

This was a proof-of-concept pilot study which aimed to demonstrate the feasibility of recruiting and treating people who suffer from chronic spontaneous urticaria (CSU) in a time-limited version (10 sessions over 10 weeks) of the WPTA, within a hospital's immunology department located in a main urban centre.

The researchers used qualitative data generated through interviews conducted before and after the therapy as well as email correspondence. The study had a dual purpose. The first purpose was to provide insight into why this approach may work for people suffering from CSU. The second purpose was to provide an information basis for a larger outcome study comparing this approach with orthodox drug and other biomedical approaches for CSU. In addition to the qualitative data, the researchers collected data regarding disease outcomes for the patients under study.

According to Lindsay et al. (2015), apart from single case reports, there had at that stage been few studies systematically attempting to explore the role of psychological intervention in CSU. This is despite PNI evidence and other research demonstrating the prevalence of psychosocial factors in this chronic illness (Chung, Symons, Gilliam, & Kaminski, 2010). Using open recruitment, patients were invited to take part by senior staff responsible for their care within the immunology department, a tertiary specialist service. The first four patients who agreed to participate were enrolled in the study. The data I analysed comprised of two open-ended interviews conducted with each patient

(their terminology); one after two therapeutic sessions, and one on conclusion of the study 10 weeks later.

For this set, I obtained ethical approval to access to both the original audio recordings and transcripts (see below). I read the Lindsay et al. (2015) publication after I completed the secondary analysis so that their interpretation of findings did not influence my analysis.

Source 2: Video interviews from the Medicine as an Art film project (Cunningham, 2015)

These interviews were undertaken in New Zealand in 2009 and were conducted with WPTA clinicians, as well as four women who were treated in this approach through private clinics. The interviews with the women who were treated by this approach were designed to form the centrepiece for the film. It was planned that the stories would be augmented with animation, photos and imagery. Analysis was carried out on the “raw” unedited footage for this project, which included exchanges between the filmmaker and the cameraman as well as “setting up” instructions to interviewees. For this data set, I had access to these video recordings which I had professionally transcribed as well.

Keeping in mind that the primary purpose of this phase was to scaffold the design and data collection of the main phase, these data sets were seen as being of sufficiently good quality to allow me to conduct my own research interviews and analysis afresh (Heaton, 2004). Firstly, and perhaps most importantly, the original recorded interviews in one case (Lindsay et al., 2015), and original video takes in another (Cunningham, n.d.), were available in their entirety, therefore allowing me to analyse the data in context. This enabled the listening and viewing of the original interviews. Not having to rely exclusively on transcripts, which could result in hampered interpretations, was a clear advantage, as transcripts may be incomplete and do not convey the at times important minutia such as pauses, laughter, tears and emphasis of speech (Heaton, 2004). Furthermore, accessing the uncoded transcripts for both data sets enabled the analysis without being “primed” by others’ interpretations.

5.2.3 Ethics

Ethics approval for the secondary analysis of the hospital interview study was obtained through my university as part of the ethics approval for the entire project. Consent to re-

analyse the interviews was obtained from each of the original participants by the original researcher.

Ethics for the use of the movie project was deemed as not necessary by my university, given that participants in the movie agreed for their interviews to be widely shared online.

5.2.4 Analytic process for the secondary data

In order to approach the secondary data analysis in a thoughtful and deliberate way (Heaton, 2004; Sandelowski, 2011; Thorne, 2008), and pay close attention to the implications of the design decisions (Thorne, 1998), I documented my approach to engaging with and analysing the data. As a consequence, a comprehensive audit trail was created to enable internal and external auditing of the development of analysis (Heaton, 2004). For each of the sections below, there is an associated appendix included specifically for this process.

5.2.5 Detailed description of the analytic process

The secondary analysis was done prior to undertaking the primary research. In order to keep the analysis focused on the key phenomenon of interest, the interviews were listened to and watched (see detailed process below) multiple times and the following anchoring questions were used to reflect on the accounts:

- How do they describe their experience? e.g., do they spontaneously use their own metaphors? What type of words do they use?
- Are some aspects of the experience hard to articulate? Contrast with those which are “easy”.
- What is not said? For example, do they contrast this care experience with others? Do they speak of the impact of the care experiences on their close relationships?
- How do they conceptualise their physical response to the WPTA? How does this contrast with the perception of the clinicians I spoke to in the consultation phase in terms of what is going on here?
- What do they talk about in terms of other things other clinicians tried to help them with their chronic illnesses? Do they compare them to the experience of WPTA care (and if so, how)?

- What are the patterns, categories, themes, I can see here?

My analytic process followed four steps. These were:

1. Naked or naïve engagement with the interviews.
2. Systematic documentation using research memos.
3. Systematic viewing and listening and highlighting key quotes.
4. Constructing themes.

Each of these is discussed in more detail below.

Step 1: Naked or naïve engagement

Because other people carried out the interviews and I did not have the prior engagement and context they had, I determined that this step was necessary for me to become familiar with the data. In order to avoid premature coding or trying to fit the data into boxes in the first analytical engagement (Thorne, 2008), this step involved absorbing the information without an intermediary. Therefore, I listened to, or viewed the interviews directly, without using the transcripts or software. I termed this stage “naked or naïve engagement”.

During this engagement, I took handwritten notes and doodles of whatever came to my mind and analytically “grabbed” me while listening/viewing, and I continuously reflected on the guiding questions outlined above. This was repeated with each source, until my notes captured, at that point, all I had to reflect on for the individual interview (see Appendix F for an example).

Step 2: First stage typed documentation

I started to organise my thinking by typing notes on key dimensions for each interview (see Box 2), consulting my handwritten notes in the process. I did this before I consulted the transcripts of the interviews, and carefully documented what further insights I obtained following reading the transcripts. In deciding on the initial sub-headings to reflect on during this stage, I drew on the writing of Thorne (2008), Hunt (2009), Charmaz (2006) and Hunter Revell (2013). An example of a memo written during the secondary analysis process is in Appendix G.

Box 2. An overview of key dimensions documented in Step 2 of the analysis.

What's going on here: What is the story? Who is the person? What did they say? What did I hear/see? This was done for me to remember the context for each person (Hunt, 2009).

Reflection on the interview: These were raw and unprocessed thoughts about the interviews. In a way, this heading allowed for “musing out loud”, of thoughts and reflections on what was said.

Methodological notes: Specific notes about the types of questions asked by the other interviewers, and questions this interview prompted me to ask. I noted under this heading methodological thoughts that could help fine-tune my own approach during the eventual primary data collection (Hunter Revell, 2013). Practical considerations such as reflecting on how to start the interview and how to address periods of silence during the interview were noted here.

Analytical interpretive notes: These were thoughts and notes that are more interpretive and analytic in nature. I documented these with the view of using them in the eventual analysis phase. I noted under these heading thoughts regarding choices participants were making in describing the process and their own emotions. For example, in response to the interviewer asking, in the second patient interview, if the person felt empowered following their WPTA session, in the Lindsay et al. (2015) study, the person is very clear in saying they felt hopeful, they were very emphatic about that. I noted this observation after the first naked listening as something worth exploring at a later stage. Indeed, this specific word was later echoed and emphasised in the primary phase.

Reflexive notes: These notes were concerned with how I felt about the interview, the emotional and the physical reactions triggered. How closely or not the person fitted with my own experience. Anything I felt could influence the analysis and interpretive process down the line. I also used this as a way of monitoring my own wellbeing throughout.

What is missing? These notes were a direct result of Thorne's writing on the analytic process. They were concerned with what I was not seeing in these interviews, which I would have expected. Specifically, in the CSU study that had a before and after interview, I reflected on what was missing internally. For example, in many interviews in the hospital study, the people hardly commented, if at all, about any specific story that may have been revealed, or the possible metaphorical nature of their illness. Whereas in the video project, where participants were “primed” in previous discussions with the filmmaker (this was ascertained from the “raw” extracts), they did talk of specific stories revealed through the WPTA.

Emerging themes? These notes were concerned with any thoughts about the themes, which were coming through in the interview. Drawing on Charmaz (2006), I carefully noted them so that, in

the final write-up, I may be able to show the evolution of a theme from naked listening in the secondary analysis to a final theme in the doctoral dissertation.

Questions to ask: In addition to the methodological heading above, I wanted to ensure I captured any specific questions the interview prompted me in asking *of the data*, as well as *in my interviewing*. Whereas above I commented on the specific interview I was listening/watching, here I was reflecting on what I might choose to explore later in the primary research.

In writing these memos, I consistently documented and dated the evolution of my thinking. In engagements with subsequent interviews, I documented any new questions and reflections I had.

Step 3: Highlighting key quotes

Following engagement with each of the interviews, I used highlighters on the transcripts to group together quotes that seemed to speak to consistent themes. This was done without naming the themes to avoid becoming “attached” to any specific name and forgo opportunities to identify alternative groupings that might shed better interpretive light on the data (Thorne, 2008).

Following this process, I started creating pictorial representations of possible themes and relationships between them on a notepad (see Appendix H for an example).

Step 4: Constructing themes

While reflecting on the relationships and possible themes, using the process outlined above, I constantly asked questions, which became increasingly complex, using the memos from each interview. Thorne (2008) advocates for neophyte researchers to focus their analysis on generating a thematic structure aimed at highlighting the key elements of a phenomenon in relation to the research question. Furthermore, as outlined previously, ID explicitly calls for method flexibility, and advocates selecting methods which are specifically relevant to the research endeavour. Therefore, I followed Braun and Clarke’s (2013) guidance on thematic analysis at this stage of the analysis, as a way of scaffolding my analytical process.

Both Braun and Clarke (2013) and Thorne (2008) are very clear that themes do not emerge from the data in a passive process, as if the qualitative researcher is an archaeologist digging to find something that already exists in its entirety. Rather, they

argue, the researcher is actively and consciously making choices on how to shape the raw data. Indeed, viewed this way, it becomes clearer that the qualitative researcher's task is to tell a particular story about the data in relation to their research question, rather than trying to represent everything in it (Braun & Clarke, 2013).

At the secondary data analysis stage, the themes were constructed with the intent that they would be refined and revised throughout the ongoing analysis. According to Braun and Clarke (2013), a theme is distinct because it has a *central organising concept*, but might contain a number of different ideas or aspects related to that concept. In order to capture the central organising concept, I developed a set of guiding questions. These were designed to help me remain critical and evaluative and allow me to stay somewhat distant from the data. Designing an approach to keep this distance is in line with Braun and Clarke's (2013) and Thorne's (2008) guidance as they suggest such distance might improve the quality of the analysis.

Guiding questions in developing candidate themes Tuesday 8 March, 2016

- Is this a theme? Check it isn't a code or a feature of the data
- Is there a central organising concept that can be applied to all the data extracts?
- Is the central organising concept one which:
 - My intended audience can relate to?
 - Is relevant to my research question?
- Is the central organising concept telling me something meaningful in relation to my research question? Does it offer something beyond what we can initially observe?
- Can I ring-fence this theme? Be able to articulate where it starts and finishes in relation to other themes?
- Can I support this theme with enough data across my entire data set?
- Constantly ask myself:
 - What is the overall story of my analysis in relation to my research question?
 - How do the themes relate to each other?

- Comment on the degree to which I believe this theme represents an idea which is core to the phenomenon of being treated in a non-dualistic way for a chronic condition.

See Appendix I for a table outlining the process of developing candidate themes following the secondary analysis.

5.2.6 Scaffolding the primary study

The interviews analysed had a different focus than this doctoral study. They were oriented towards the meaning-making aspect for the person being treated. Accordingly, the questions focused on the participants' sense-making of their illness as a consequence of their therapy. Little questioning was done with respect to their illness experience to date in the healthcare system, the WPTA therapeutic experience or therapeutic experiences with other clinicians. Nor was there questioning of how previous experiences in the health system might relate to their current experience.

Therefore, the findings from this phase were used to inform the design and analysis of the primary study (see below). That is, the tiered process of undertaking the secondary analysis first, informed who was interviewed, and how the primary data were collected and analysed. The findings from this stage were also used as a "sense-check" of the themes constructed in the analysis of the primary study. However, the analysis of the data from the primary study was done afresh. The findings constructed following the secondary analysis are presented in their entirety in Appendix I. In Chapter 6, it is clearly articulated how findings from the secondary analysis were used to sense-check the analysis. The extent to which the methods for the primary study were informed by the secondary analysis is described below.

In addition to the analytical value the secondary data contributed to the overall study, which is discussed in further detail in the findings chapter, the secondary analysis process informed the design of the primary research in two important ways:

- a) The approach to purposeful sampling of participants and the clinicians they worked with; and
- b) Designing the interview guide.

A common feature of the participants of both the secondary data sources was their homogeneity in terms of gender, age and cultural background. In addition, the WPTA treatment approach they experienced was strongly psychotherapeutically based. All but

one of the participants, in both sources, were white middle-aged women with English as a first language, and most of the participants were treated by an expert WPTA physician who was also psychotherapeutically trained. The one person who was not treated by this physician was treated by another psychotherapist.

As a consequence, in undertaking purposeful sampling for the primary study, a deliberate effort was made to recruit men, different ethnicities and a wider range of ages, including younger participants as well as much older ones. Similarly, I also aimed to recruit participants who were treated by a cross section of clinicians.

Secondly, as noted above, the focus of the interviews in both studies was on the participants' own sense-making of how they saw their own illness as a consequence of the WPTA experience. There was little or no exploration of the therapeutic relationships. This influenced the design of the semi-structured interview guide so that I would be better able to explore in-depth the various therapeutic experiences, with the explicit aim of generating insights for mainstream practice.

5.3 Step 3: The first phase of the primary study – Hospital setting

In this step, I outline the details of the primary study, including the approaches for collecting the data, purposive sampling, description of the recruitment process, recruitment locality and how the data were analysed.

5.3.1 Data collection

Semi-structured interviews were the primary form of data collection. Semi-structured interviews were deemed appropriate for this research because their use is consistent with ID as they allow the researcher to stay focused on the phenomenon of interest while remaining open to the interviewee's perspective and individual experiences. However, they also present some challenges, as participants choose what they want to articulate in this context. Indeed, given the co-constructed philosophical underpinning of the proposed research, it is important to acknowledge that individual recollections are subjective, no matter how vivid or touching they might be (Thorne, 2008).

Acknowledging these challenges, and in order to facilitate the clinical relevance of the findings, I employed a "toolbox" approach to my interviews. The toolbox comprised a range of techniques. These included different types of approaches to questioning, inviting participants to bring an object, which was meaningful to them in the context of the WPTA therapeutic relationship, and timelining. I consistently and explicitly

reflected on the quality of the interviews and the appropriateness of the interview guide throughout, as part of the memoing process (see Box 3). Consequently, the techniques and approach to the interviewing continually evolved and adapted (Sheridan & Chamberlain, 2011). See Appendix J: Evaluation overview of interview guide for details of the adaptations made to the interview guide throughout.

The key tool utilised throughout the research was timelining. Timelining was initially explored in the pre-pilot phase and ended up being utilised extensively throughout the data collection process because it appeared to generate comprehensive and nuanced responses, which underpinned the analytical process.

5.3.1.1 Timelining

Following the guidance offered by Sheridan, Chamberlain, and Dupuis (2011), I started the interviews by stating that I knew nothing of the participant's medical condition or history and invited them to tell me the story of their symptoms and chronic conditions and to help me identify key trajectory points in their experience of their symptoms on a large piece of A3 paper. I used colour markers to draw a line across the landscape page, from the time they first started to experience symptoms until the time the interview was taking place. I gave each participant a pen, and invited him or her to write along the timeline as well or to correct me if I got anything wrong. I asked them questions regarding when the symptoms started and when they received a diagnosis (if that was relevant). Through this process, I invited participants to reflect on the types of experiences they encountered, and when they first encountered the WPTA. I utilised this approach to enable exploration of their care experiences in a potentially unthreatening way which may have helped anchor their recollections (Sheridan et al., 2011). See Appendix K for an example of such a timeline.

5.3.1.2 Meaningful objects

Participants were also invited to bring meaningful objects that might help them tell me their stories (Sheridan & Chamberlain, 2011). In the first 10 interviews in the hospital, no participants brought objects with them. After reflecting that this may have been experienced as too personal (in my methodological memoing), I stopped asking about these objects. However, two participants who saw physiotherapists did bring objects with them. These objects were photographs, which I photographed, though the images are not included here to maintain participant anonymity. In the analytic process (see

Step 4 below), I referred back to these photographs as a visual aid, when analysing these two specific interviews.

5.3.1.3 Collecting demographic data

I opted to collect demographic data once the interview was concluded rather than at the beginning. I focused the beginning of the interview on establishing rapport with participants to make them feel comfortable and able to share. In the context of my professional background, closing interviews with asking demographic questions is common practice, as participants in commercial research indicate they prefer to be asked such questions after they have concluded the interviews and feel safe in sharing these data with the researcher. The demographic details collected were: illness or symptoms description, duration of experiencing the symptoms, age at the time of the interview, participants' description of their ethnicity, whether English was their first language and gender.

5.3.1.4 Initial aim to include thoughtful clinicians as participants

Thorne (2008) advocated including thoughtful clinicians in an ID project. She argued thoughtful clinicians have access to numerous case studies, and may well be able to add perspective and insight on phenomenal variations that far exceed the reach of most qualitative studies.

In this doctoral research, one of the supervisors acted as a “thoughtful clinician”. This supervisor initiated the postgraduate course on WPTA, and is an experienced physician, and psychotherapist, and one of the clinicians from whom I recruited participants. This supervisor acted as a mentor throughout the research process, continually questioning my approach, findings, and pushing my analytical thinking through posing thoughtful questions and highlighting areas to explore further. Furthermore, clinicians' perspectives were utilised from the outset, especially during the pre-confirmation consultation phase, discussed previously in Section 5.1.1 of this chapter, and their perspectives and thoughts were factored into the design throughout.

It was, indeed, my intention at the outset of the study to include more thoughtful clinicians in the research; formally interviewing them once the analytic process of participants' interviews was complete. However, following the completion of the analysis, and in discussion with my primary supervisor, I decided that formal interviewing of thoughtful clinicians might result in a shift from the primacy of the participants' experiences.

5.3.1.5 Transcription and data presentation conventions

The interviews were audiotaped and transcribed verbatim by a professional transcriber. The transcripts followed orthographic style which constituted a strict record of what participants actually said in the interviews. As a consequence, the transcripts included all false starts, repetitions and filler words. They also retained grammatically incorrect speaker idiosyncrasies. Every transcription line was numbered and recorded times were captured throughout.

5.3.1.6 Sample size

According to Sandelowski (1995), it is a misconception that numbers are unimportant in qualitative research and that, in the context of health research, if sample sizes are perceived as inadequate, the credibility of the findings to clinicians can be undermined. She further clarifies that, in addition to number of persons, sample size in qualitative research could also refer to number of events, or interviews done, and that different sample sizes are appropriate for different qualitative methodologies. Thorne (2008) is explicit that ID can be used with samples of most sizes and that it is most commonly used with samples of between five and 30 participants. Given the practice orientation of this research, reaching a sample size which would be seen as credible by clinicians was a consideration. The key recruitment consideration, however, was generating findings with the capacity to resonate and influence practice.

Accordingly, during the primary study, analysis and data collection were carried out concurrently. Therefore, at each step, additional interviewing was carried out only if it was seen to enhance the capacity of the findings to answer the research question. In total, the sample size for this research comprised of 29 units of data:

- a) The secondary analysis of 11 interviews undertaken by previous researchers.
- b) The first phase of the primary study: 10 interviews with people seen by WPTA clinicians in the immunology department.
- c) The second phase of the primary study: 8 interviews with people seen by two WPTA physiotherapists.

Following the first 10 interviews conducted with hospital participants, the decision to interview people who saw physiotherapists was undertaken to expand the heterogeneity of the experiences researched. The rationale for this expansion is outlined below in Step 4. Following the analysis of the 11 secondary interviews and 18 primary interviews and

in discussion with my supervisors, it was decided that the data gathered, and the concurrent analysis, were sufficient to address the research question.

5.3.2 Sampling and recruitment

Purposive sampling of a phenomenon is a technique where the research setting or individuals within them are included because they represent some angle of the experience or phenomenon being researched (Sandelowski, 1995, 1999, 2000). The aim is to capture a diverse range and breadth of experience, which could help render the eventual findings credible to the intended audience of the research (Sandelowski, 2000).

There were three key inclusion criteria for the research participants: a) living with a chronic condition, b) who have been treated by the WPTA method since 2013 – so that the experience would be relatively fresh in their minds for meaningful comment, and c) who can speak conversational English. Given, as noted above, data used in the secondary analysis were primarily from white, middle aged women with English as a first language, I initially focused on recruiting men, and on achieving greater diversity of ethnic backgrounds and ages. I considered this greater diversity of participants' characteristics a potentially good source of information about how the WPTA is experienced which could enhance the analytical goal of this study (Sandelowski, 1995).

5.3.3 Recruitment locality – Tertiary Hospital Immunology Department:

As outlined in Section 5.3.2, the recruitment for the first phase of the primary study commenced in a hospital-based immunology department. This research setting offered access to individuals who were seen in an outpatient day clinic for their, often chronic, immunologically related conditions. Only individuals who were seen by WPTA clinicians in this setting were approached.

There were three clinicians in the immunology department who taught or trained in the postgraduate MindBody diploma in AUT, two of whom have led the diploma at one stage. They included a medically trained immunologist and psychotherapist, a medically trained immunologist and rheumatologist, and a clinical dietician. In this setting, the WPTA is adopted from the first consultation alongside the normative dimensions of immunological care, which may include medication or food challenges, as deemed necessary by the treating physician. The treatment each referred person receives depends upon the clinical judgement and skills of individual clinical staff (Lindsay, Goulding., Solomon, & Broom, 2013).

Within the department, there is no distinction between those clinicians who are formally trained in WPTA and those who are not. The majority of patients are allocated to clinical staff on a random basis by the triage clinicians. In some cases, the referral letter from the general practitioner specifically asks for a person to be seen by one of the WPTA clinicians. Further, where there is sufficient information in the referral letter for the triage clinician to determine that an individual may specifically benefit from the WPTA, they might allocate them purposely. However, these last two routes are infrequent and the vast majority of people seen by the WPTA clinicians in the department were allocated randomly to them. Therefore, most patients who encounter the WPTA clinicians do so as they would any other medical professional in an outpatient clinic. They are referred to them through the hospital referral system and they are treated in outpatient consultation rooms. Because of the focus on chronic conditions, and the opportunity this context affords for these people to reflect on the care they receive within the “mainstream” structures, it was decided that initially, the primary data collection would begin there.

Clinicians were asked to focus their support for recruitment to the study based on the purposive sampling criteria outlined above. Eligible people were approached by their clinicians with an outline of the study. Clinicians mentioned the study briefly and gave them the detailed information forms. The clinicians then provided me with contact details of those persons who agreed to be approached, and were interested in finding out more about the study. I followed up, or attempted to follow up by phone, with all the people who expressed an interest. In line with the ethical approval, I only attempted to contact people up to two times. Once contacted by phone, I outlined the study in greater detail and provided opportunity for questions. Potential participants were also offered thinking time. All of the people with whom I made contact agreed to take part during this initial phone call. I could not contact three people, and one person agreed to be interviewed but was not available because of travel at the time interviews took place. For detailed information and contact forms used, see Appendix L. From their own accounts, the majority of participants appeared to have been referred to the WPTA randomly.

5.3.4 Ethics

Ethics approval for the primary study was obtained through my university (see Appendix M for the final approval letter). As part of the university ethics process, I was

also required to obtain a separate institutional approval from the health board (see Appendix M).

5.3.5 Analytics process

Below, I detail the analytic process undertaken continually during the primary interviews. Given that ID does not provide a detailed “cookbook” approach to analysis, I continually documented the steps I was following, the devices I was utilising such as memoing, and any changes I was making to these throughout.

Consistent with ID and other qualitative methodologies, the analytic process was undertaken concurrently with interviews. After each interview was transcribed, I commenced analysis. As a consequence, the analysis of each interview informed subsequent interviews and enabled me to ask questions clarifying aspects of the analysis throughout. I followed my initial interview guide, but as a consequence of this process, I was able to focus on specific areas identified in the preliminary analysis. Analysis of each interview followed the steps outlined below.

5.3.5.1 Naked or naïve listening and systematic memo generation

As in the secondary analysis, memoing was used extensively in the primary study. Borrowing and adapting from grounded theory (Charmaz, 2006), the practice of disciplined memoing, as a way of providing a decision trail which explicitly demonstrates the inductive reasoning process throughout the analysis, is advocated in ID research. This is argued to enhance the analytic logic of the findings (Thorne, 2008).

Of specific relevance to my study was the work of Hunt (2009). In his article drawing on his experience of using ID for an inquiry into the moral experience of clinicians in humanitarian work, Hunt (2009) described how he created memos to chronicle his reflections and perspectives on individual interviews. He also used them as a way to interpret and understand the data and refine his categories and codes.

I followed Hunt’s (2009) approach and that of Hunter Revell (2013) by writing a synopsis of each interview and returning to these at various stages of the analysis to remain mindful of the whole of each participant’s story. This process was helpful, as I did not lose the coherence of each narrative during the process of comparative analysis (Charmaz, 2006). The recursive memoing approach, where I wrote memos for each interview on at least three occasions (after the interview was conducted, during naked or naïve listening, and once the interview was transcribed), helped me maintain awareness of the potentially idiosyncratic aspects of individual participant’s experiences. This

awareness in turn enabled me to be aware of the ways particular life narratives of individual participants might have shaped their experience of the WPTA.

As detailed above, the primary analysis was done afresh; however, I drew on the secondary analysis during this phase and used the memoing process to document where the themes identified in the secondary analysis phase were strongly evident. In a way, the secondary analysis process served as a foundation for the primary research. The secondary analysis helped stimulate my focus and acted as an additional check allowing comparison of my themes with those of the other interviews, whilst being mindful that they were collated for a different purpose. Box 3 provides a description of the sub-headings within each memo used during the primary analysis. For an example of a memo written during the primary analysis which refers to the secondary analysis process please see Appendix N.

Box 3. Description of hospital interviews primary analysis memos' sub-headings.

What's going on here? This was a narrative aimed at capturing the context and the illness story of each of the people (Hunt, 2009; Hunter Revell, 2013), heavily drawing on the notes and the narratives prompted by the timelining process (Sheridan et al., 2011). I also captured under this heading any descriptive impressions with respect to what was happening for this person as a consequence of experiencing the whole person approach.

Interpretive analytical: Documenting where I was starting to make connections and interpretations that went beyond the descriptions in the first memo (Hunt, 2009). I used this heading to provoke deep reflections on the specific interview vis-à-vis previous interviews, including those analysed during the secondary analysis process, where those were "provoked".

Themes/asking complex questions: Where I sensed that there were some strong themes coming through, I documented those (Charmaz, 2006). Where this happened through the co-construction process with the participants I noted that. I used this heading to reflect on what was present and what might not have been present in the interview.

Theoretical: This memo was designed to make explicit connections between the interview and any theoretical framework from the literature, in an effort to capture, without pre-empting or being "bound" to, a particular theoretical framework. I used this reflection as a kind of "quality check" to demonstrate I was being conscious of not being captured by a particularly appealing theory and try to have the data "fit" the theory.

Methodological: Throughout the interviews, I critiqued my own approach through listening to the interviews in their entirety (Hunter Revell, 2013). For example, through writing these memos, I documented that my intention to have an object that reminded them of the relationship with the clinician was not a useful approach. I also consistently documented how the illness "timelining" proved useful and helpful. In addition, I came to be increasingly more cautious in my choice of words to encourage my participants in their articulation of the experience as a consequence of these reflections. For example, rather than say, "I understand", I became aware that it would be more appropriate in the context of the interviews to say phrases like, "*I think I understand but could you please elaborate more*".

Reflexive: Under this heading, I documented both the emotional impact the interview had for myself, as a measure of researcher safety, as well as another way to document what may resonate strongly or not in the interview.

5.3.5.2 First coding in NVivo

Initially, I generated preliminary codes for analytical experimentation from the memoing process described above. It is important to note that these were based on the data, not my own reflections. That is, each code was based on extracts from the interviews and noted in the memo during the initial naïve listening process. Using these

preliminary codes, I coded all of the hospital interviews in NVivo, adding more codes during the analysis of each transcript, and documenting when each code was added. Twenty-five codes were generated from this process and these included codes concerning self-insights, discomfort, communications, listening, professional expertise, patients' own expertise, illness experience and making connections.

Using NVivo enabled me to view combined extracts for each code, begin the analysis and experiment with a preliminary thematic structure. Following the analysis of the first eight interviews, my supervisors and I met and critically discussed the emerging thematic structure.

5.3.5.3 Critical reflection on the data utilising sensitising concepts and the process of asking increasingly more complex questions

As documented in Chapter 1, at the outset of this work, I had made three assumptions about what had facilitated my own strong recovery as a consequence of undergoing the WPTA. First, that understanding and internalising how "my life's story" was interlinked with my own illness, was key to my recovery. Second, that I was ready to enter such a therapeutic relationship and therefore was able to engage and benefit from it. Third, that the quality of the therapeutic relationship my clinician established between us enabled the success of this approach through establishing a safe environment. These assumptions were purposefully and explicitly incorporated into the analysis as sensitising concepts.

According to Charmaz (2006), sensitising concepts are a set of general concepts which can give researchers ideas to pursue and be sensitised to, so that they can ask a particular set of questions about the topic under investigation. The sensitising concepts are used not as a framework to be imposed on the data, rather, as explicit questions to ask of it. Indeed, I used these three sensitising concepts throughout the analysis in how I framed the questions asked of the data. In undertaking this analysis, I critically interrogated descriptions of first WPTA encounters and subsequent encounters with three key questions relating to my assumptions in mind:

1. What happens in that first encounter that shapes the clinical relationship?
2. What is the role of "readiness" in these first encounters?
3. What is the person's view regarding the centrality of their story in their own illness experience and how does this awareness shape how they come to see their condition?

Furthermore, my “thoughtful clinician” supervisor provoked my analytical process by asking specific questions regarding the emerging insights from the NVivo analysis. Specifically, questions were asked regarding the concept of listening, which was identified very early on as key to the experiences. The supervisor specifically asked the following questions: What was it that the clinician was listening to, which was helpful? Was it important from the patient perspective what the clinician was listening to? What made the listening relevant and crucial in some way?

I expanded on the questions that had arisen from my own assumptions and my supervisors’ contribution and continued the process of using questions as a way to interrogate the data with additional concepts that were highlighted as relevant to the research question. For example, through the timelining process, participants spoke at length of the ways their illness affected their lives, or to put it another way, they spoke of their suffering. As a consequence, I asked the following questions: What were the ways participants described their own suffering? Did the medical system increase their suffering, and if so, how? What were the ways in which communications/relationships with medical professionals added to their suffering?

In contrast to the concept of suffering, participants also used the timelining part of the interview to speak of ways in which experiences with the medical system and medical professionals relieved their suffering, including WPTA and other clinicians who were not WPTA. These descriptions prompted the following questions: What were the ways relationships with other health providers relieved their suffering? What were the ways they describe how their suffering was relieved through receiving the WPTA? Do they go beyond the ways described above with other non-WPTA clinicians? What did “not suffering” look like for this person?

The same process of asking questions of the data was done for the remaining concepts that were identified through the NVivo analysis. These included exploring the salience of medical professional identities for participants, as well as what it meant for participants to be treated as persons. I specifically focused on trying to understand what it was that participants took from the WPTA experience.

I used these questions to critically reflect on the transcripts, extracting quotes which “spoke” to each of the questions into a table format in Microsoft Word. I used this format to reflect on the quotes, noting analytical thoughts alongside the questions and

the quotes. I also used this document as a way of communicating my thinking and analysis on an ongoing basis with my supervisors (see Appendix O for an example).

5.3.5.4 *Generating themes:*

The tables referred to above, and my sets of analytic notes for each interview, allowed me to ask questions in an increasingly complex manner. In addition, because I personally conducted these interviews, I was conscious and continually aware of the co-constructed nature of the ideas and eventual themes emerging from this process. The memoing process continued to serve as a way to provide a sort of quality assurance for this process. I carefully documented the active and conscious choices I was making on how to shape the “raw data”. Through this process I became very focused about telling a particular story about the data to answer the research question, rather than trying to represent everything in it (Braun & Clarke, 2013). As with the secondary data analysis stage, the themes were constructed with the intent that they would be refined and revised throughout the ongoing process of analysis.

In analysing the interviews with hospital participants, I constructed preliminary themes around five “topic headings”. These themes were generated from the data, and were extensively illustrated with direct quotes. I presented them for discussion to the supervisory team and it was agreed to revisit those themes once the analysis of all the interviews was complete.

Following the analysis of these interviews, it emerged that if all of the interviews were carried out in this one public hospital setting, there was a risk that the research would generate overly context-specific conclusions (Thorne, 2008). This was determined for two key reasons. First, the department is unique as there are three WPTA clinicians operating from the same location. Arguably, being in this physical proximity offers opportunities for spontaneous mentoring and support for the WPTA clinicians, whereas the majority of WPTA clinicians operate individually in disparate and often private settings.

Secondly, the interviews revealed that the WPTA practised in the department is focused on talking with the person about their life stories and listening to those. Furthermore, a number of patients seen in the department by the WPTA clinicians were referred on to WPTA trained psychotherapists for more in-depth psychotherapy, including five out of the 10 people interviewed. Although the focus of the interviews was on participants’ experiences of the WPTA within the hospital setting, I felt it important to seek further

perspective from people who were seen by WPTA clinicians who incorporate this approach in a different clinical setting altogether. Indeed, the WPTA is taught to a cross section of clinicians including a number of physiotherapists (Broom & Joyce, 2013) who are more “touch” focused in their practice. In the second phase of the primary research, theoretical sampling was used to guide recruitment of people seen by WPTA clinicians outside of the hospital setting, where “touch” played a more integral role in the therapeutic encounter (Sandelowski, 2000).

5.4 Step 4: The second phase of the primary study – Participants who saw physiotherapists

5.4.1 Including physiotherapists and selecting clinicians

Two “exemplar” WPTA physiotherapists were identified by the two WPTA physicians who taught in the MindBody postgraduate course (see Chapter 2, Section 2.3.1.1 for more details). They were in agreement regarding these two physiotherapists who were observed during ongoing training as demonstrating a sensitivity of practice and a deep understanding of the WPTA. These two physiotherapists were approached and were invited to identify people they had treated using the WPTA and who would be eligible to take part in this research. More detail about the specific practice settings of these clinicians is included below.

5.4.2 Second recruiting locality – First physiotherapist operating in a private physiotherapy clinic in central Auckland

This clinic is run by a WPTA trained physiotherapist and is advertised as treating the whole person rather than just the condition. Clinic communications make it clear they provide strategies for ongoing body health. They treat all types of musculoskeletal conditions including neck and back pain, shoulder and elbow dysfunction, chronic pain, postural imbalances, and breathing disorders, whether they are injury- or stress-related.

The recruitment process followed the same steps as the hospital recruitment. The clinic is based in a wealthy suburb of Auckland, New Zealand. It is a private clinic and so those receiving treatment in the context of a chronic condition pay for their services. While I did not collect socioeconomic data, it is likely participants recruited from here were likely well-educated and relatively high income-earners.

5.4.3 Third recruiting locality – Second physiotherapist operating from an integrated health clinic in AUT North Shore

The second clinic offered access to a potentially more diverse group of people. This was a university-based clinic, which follows an inter-professional collaborative model and is open to anyone in the community. It can be accessed with or without a referral from a family doctor/general practitioner. Most of the services are provided by final year and postgraduate health science students who are supervised by a highly experienced clinical team.

The exemplar WPTA physiotherapist is one of the clinical educators, and she works privately as well. The people seen by this clinician in her capacity as a clinical educator are seen in the context of a training session with a senior physiotherapist student present. The recruitment process in this locality followed the same steps as outlined previously.

5.4.4 Ethics

Ethics for interviewing people who saw physiotherapists was covered by the original ethics approval from my university (Appendix M).

5.4.5 Analytic process

I followed a similar analytic process to that which I used with the participants who saw the hospital clinicians; however, it differed in two key ways. First, I used different memo headings during the naked or naïve listening and systematic memo generation process. This was done as the evolution of my thinking resulted in identifying different areas to reflect on, and to further fine-tune the emerging themes. The memos are described further below.

Second, I decided to abandon the coding process in NVivo and exclusively focus on analysing the data in the original Word format. I did this by reflecting on the themes identified in analysing the interviews with hospital participants and by asking questions. I found the process of asking questions of the data extremely helpful in deepening and extending my thinking. However, I found using NVivo was too restrictive, and not supportive of this way of explicitly using a questioning technique in reflecting on the data. Indeed, Thorne (2008) cautions extensively on using software in small-scale qualitative research endeavours as she sees the structure of such software as restricting the analytic process. She instead advocates the disciplined and creative use of Microsoft Word or similar. Many of the steps followed for this data set were the same as those

outlined above. Therefore, I present the new steps introduced in the evolution of the analytical process.

5.4.5.1 Naked listening and systematic memo generation

Box 4 below describes the different memo sub-headings I used in this stage.

Box 4. Description of physiotherapy interviews primary analysis memo sub-headings

What's going on here? This heading remained consistent throughout, and served as a way to maintain the balance between staying close and respectful of the individuals and their stories, while moving to generate increasingly more abstract and complex questions, observations and eventually themes and overarching concepts (Hunt, 2009; Hunter Revell, 2013).

How is it similar to interviews with hospital patients? This and the subsequent memos were only introduced at this stage to allow me to critically reflect on the ways the experiences here were similar and different to those of the hospital patients. I specifically commented on whether the themes I constructed were present. I also used this heading to reflect on other ways in which the interviews revealed things I had heard/seen before (Charmaz, 2006).

In what ways is it different/unique? Here I reflected on the ways in which the “touch” experience and the professional focus of physiotherapists on the mechanics of the body may lead to a different experience by the person being treated. I was attempting to critically reflect on the data by asking: What am I not seeing here? What is said and not said? (Charmaz, 2006; Thorne, 2008)

Emerging themes? Complex questions to ask? I specifically reflected under this heading on the broad groupings that could be made in the interview and relating those to previous ones. I also identified under this heading new questions that could be asked of the data.

Methodological: I continued to critique my approach to interviewing, building on the semi-structured interviews, adding new questions and different ways to elicit responses (Hunter Revell, 2013).

Reflexive: The description here remained consistent throughout.

For a detailed example of a memo written after an interview with participants who were seen by WPTA physiotherapists, see Appendix P.

5.4.5.2 Assessing whether the themes identified in the interviews with hospital participants were present in the current interviews and critical reflection on the data

This was done primarily through engaging with the transcripts, and identifying whether there were data extracts that clearly illustrated the themes previously constructed. This was done using a table format. The table clearly delineated between quotes from hospital interviews and those from the participants who saw physiotherapists. On the table, I commented alongside the interviews what I was seeing, what was in common, and what the differences were. I continued to ask further questions. These tables allowed me to refer back to the raw data in a grouped way, and attempt to make more nuanced observations.

5.4.5.3 Asking questions and the use of sensitising concepts

Throughout the iterative process of interviews and analysis, I identified further questions that could be asked of these data in addition to the ones outlined above. Once I completed all eight interviews, I used different questions this time to construct a table, similar to the one done with the hospital interviews. As with the hospital interviews, I extracted verbatim quotes to help me explore the questions. The questions asked of this data set concerned the specific experience of being seen by physiotherapists. I specifically attempted to understand what the WPTA “looks like” in combining touch and talk in the context of physiotherapy, and how this was experienced by participants. The questions were worded in an effort to gain a deep and nuanced understanding of the nature of the experience. See Appendix Q for a sample of this table.

5.4.5.4 Generating themes and further analytical concepts

Following the completion of the interviews, I constantly checked back to compare which of the themes identified with hospital participants were also present with people who saw physiotherapists. Indeed, even though all the themes identified with hospital participants could be observed with these participants, some themes, when considered across the entire set, were less evident and some became more so. This is discussed in detail in the findings chapter.

5.4.5.5 Conceptual memos

Once the analytic process detailed above was completed for all participants, I searched for a way to bring all the parts of the analytic process, including the secondary analysis, together. I searched for a way that would remain faithful to the inductive reasoning process central to ID, and contribute to a reader’s confidence in the analytic logic

applied (Thorne, 2008). Given how useful I found the memoing process as a way to refine and challenge my thinking and analytic reasoning, I set out to write three conceptual analytical memos. These memos allowed me to reflect on the analysis as a whole, the analytical process to that point, and to attend to the three synthesising concepts in beginning to attempt to answer my research question.

Using this final memoing approach, I was able to construct a thematic structure to answer my research question. The thematic structure comprised four overarching themes. The memos can be read in their entirety in Appendix R.

5.5 Step 5: Orienting the reader towards the findings as whole

Once the analysis was complete, I searched for a way to communicate the essence of the analysis in a crystallised and engaging way (Becker, 1986). In adopting ID, I explicitly accepted the challenge of making my findings accessible to health professionals, aiming to extend their insight for practice, and contribute to the collective effort of sense-making in the context of the variable and eccentric reality of health application (Thorne et al., 2004). Indeed, Tracy (2010) proposes that aesthetic merit is a key component of resonance in qualitative research, that is, the ability of research findings to affect the intended audience towards generalisation. In short, resonance may be fundamental for impact. Tracy (2010) also argues that qualitative text that is presented in an evocative and artistic way that is vividly engaging has the capacity to move the reader and encourages them to feel, think, and perhaps change their behaviour as a consequence.

When presenting this challenge in a writing workshop, it was suggested to me to find a way to tell a story in order to achieve this aim, as telling a detailed and nuanced story of a medical encounter is the best way to convey the experience and engage the reader (Jones, 2014). In medicine, and other clinical professions, the use of case studies, or stories of patients, is utilised frequently, especially in teaching (Montello, 2014). The people I interviewed told me stories of their lives, their conditions, their symptoms and their encounters with medical clinicians. I, in turn, analysed and interpreted these personal stories to answer my research question. I realised that in writing about the experiences of patients who were treated as *whole*, I ought to also include *whole* stories in the way I conveyed the analytical findings.

However, in the context of the present study, using vignettes could raise methodological and ethical complexities. First, in using ID, the purpose of the analysis was to go beyond any single case and produce an analytical product, which encompasses the

essence of the phenomenon studied (Thorne, 2008). Following this logic, no single case study could possibly capture the entire nuance of the analysis. Furthermore, in such a small-scale study, where participants had a wide range of symptoms and conditions, the risk in providing any specific detail could result in compromising the anonymity of both patients and their treating WPTA clinicians. Therefore, I decided to construct a composite interview encounter, or vignette.

The use of vignettes in research is well known, most commonly in the data collection phase as a way to elicit responses from participants (Blodgett, Schinke, Smith, Peltier, & Pheasant, 2014; Spalding & Phillips, 2007; Wilson & While, 1998). I decided to use a vignette as a way of conveying the richness and depth of participants' experiences, while protecting both their identities as well as those of their treating clinicians. I followed Spalding and Phillips (2007) approach to constructing composite vignettes and constructed a composite interview vignette. My vignette, Emily's story (presented following the findings), was constructed based on the entire data set, including the interview data on which the secondary analysis was conducted, as way of conveying and supporting key aspects of the analysis (Ely, Vinz, Downing, & Anzu, 1997).

5.5.1 Methodological approach to constructing vignettes

The interviews were semi-structured, and the use of the timelining method created a space for participants to tell their stories. This is in line with the first step recommended for employing vignettes as a strategy for presenting the voices of a vulnerable group (Blodgett et al., 2014). In constructing Emily's story, I chose a condition that is common (eczema and allergies) and constructed it in a way that illustrated the key themes. I did this by weaving together a tapestry of verbatim quotes from the entire data set. As such, the verbatim quotes in Emily's story are from women and men of varying ages and diagnosed illnesses. These verbatim quotes are clearly identifiable in *italics* and "quotation marks" and have not been edited in any way (Ely et al., 1997).

Emily's composite interview vignette is a quilt or pastiche that weaves together multiple perspectives and accounts that attempt to communicate, as a whole, the essence of the analysis (Ely et al., 1997). I chose the format of an interview as a way to introduce an additional layer, which speaks to the co-constructed nature of the interview process. As the interviewer and primary research instrument, my interviewing technique is integral to the findings obtained. By choosing this format, my intention was for the reader to gain an insight into the content, as well as the process, of the interview. Furthermore, in choosing to write an interview as this single expanded vignette, I was explicit about my

own voice and therefore when I used actual quotes of my questions from real interviews, these too are clearly marked by italics and quotation marks and retained any grammatical errors that may have occurred (Spalding & Phillips, 2007).

The writing of Emily's story in itself turned out to be a creative, and important, part of the analytic process. It offered a further way of checking the rigour of the analysis. In constructing the story to convey the key themes, I was able to test whether the inductive themes could be written into a coherent story narrative that resonated. That is, writing Emily's story offered a sort of a top-down perspective for the bottom-up, inductive, analytic approach.

5.5.2 Ethical considerations in constructing the vignette

Constructing powerful stories or vignettes of patients' experiences can be a double-edged sword. On one hand, they can be emotionally engaging and powerfully illustrate the key aspects the writer wants to convey. But on the other, they can also be seen as putting forward just part of the story, and in some cases may be even seen as a manipulative way of telling one story (Jones, 2014). In constructing the composite vignette, I followed Jones (2014) caution to use them responsibly, pay close attention to the detail, and structure the story of Emily's interview in such a way that competing positions and stories are considered, while illustrating the key aspects of the analysis.

To preserve everyone's anonymity, I deliberately chose a very common condition seen by immunologists – eczema and allergies – and a life narrative that related to many of the interviews. However, by quilting in the quotes from the interviews, I felt confident that despite this rather generic patient's story, Emily's account remained nuanced, rich and illuminating, and therefore reflected the whole of the data set.

5.5.3 Resonance check vignette

Unlike a case study, the composite vignette does not tell a story of a particular, real-life patient (Ely et al., 1997). Given that, and that the key audience for this research was clinicians who are accustomed to encountering case studies based on actual patients (Ely et al., 1997), it was important that the vignette “ring true” for clinicians who work with people with chronic illnesses. Therefore, I invited the clinicians who were involved in supporting recruitment of participants to review the interview story and comment on the extent to which they felt it could be an actual patient telling their story. Some of the clinicians who responded felt that due to the constructed nature of the vignette, it “kind of” sounds like a patient story but not completely. When probed, the clinicians

commented that the patient sounded very articulate on the one hand, but too dualistic on the other, and that they could see it as a pastiche, as no one patient, in their experience, had presented all of the elements communicated in the vignette. Nonetheless, despite these recognised limitations, the vignette resonated for clinicians and it was decided to include Emily's story as a way of bringing the findings to life, but to be transparent and explicit about the reasons for doing so and the approach taken in constructing it.

5.5.4 Positioning the vignette in the research report

Initially, I intended to have Emily's story introduce the findings, as a way of orienting the reader towards the whole before breaking it down to the parts that make the analysis. However, after discussion with the supervisory team, I became aware that, in doing so, the vignette might come across as too pre-emptive or even manipulative for some readers. Therefore, I have decided to position the vignette after the findings and before the discussion, so that the reader can read the evidence first and reflect on the composite story as a way of giving life to these findings.

5.6 Enhancing quality

Throughout this chapter, I attempted to explicitly enunciate the aspects of this research that were used to enhance the quality of this research. These included detailing the steps undertaken to incorporate explicitly reflexive practices, such as the pre-pilot interview, two positionality interviews and the ongoing memoing process. As a consequence, reflexivity is woven throughout this doctoral research from Chapter 1 through to the conclusion and postscript remarks. In line with Sandelowski (1993), I attempted to achieve rigour by making the research process as visible and auditable as I could, through detailing the steps, providing justification for their use, and offering examples in the appendices. The analytic process is made visible in a similar way so that external auditing is made possible (see Appendix S for a detailed and sequential account of the analytical process with illustrative examples). Consideration of resonance, credibility and fidelity were addressed in part through constructing Emily's story. And thick descriptions are utilised throughout the findings chapter to explore what is implicit and assumed in participants' experiences.

Chapter 6: Findings

The patient who comes to us has a story that is not told... To my mind, therapy only really begins after the investigation of the wholly personal story. ... In therapy the problem is always the whole person, never the symptom alone. We must ask questions which challenge the whole personality. (Jung, 1963, p. 118)

Through the analysis process, I constructed four themes. This chapter begins with information about the participants who contributed to the two data sources used for the secondary analysis. I then move on to outline key characteristics of the participants who took part in the interviews during the primary research. Then, each of the four themes and associated sub-themes are described and interpreted in detail.

6.1 Participant details: Secondary analysis

6.1.1 Video project

Data were four segments of video interviews (see Section 5.2.2 for a complete description) undertaken in 2009 by an independent film maker (Julie Cunningham) as part of a planned documentary on Medicine as Art (unpublished). The interviews were conducted with women who suffered from a range of chronic conditions including cancer, migraine, rheumatoid arthritis, and asthma.

6.1.2 Urticaria study (Lindsay et al., 2015)

Seven transcripts were analysed of interviews carried out with one male and three female patients who participated in the study. All participants suffered from urticaria, were more than 30 years old, and were from countries where English was the first language. The interviews took place before and after a short course of treatment (10 sessions) drawing on the WPTA. For one participant, only the first interview was made available.

6.2 Participant details: Primary research

Eighteen people with chronic conditions were interviewed for this study. They were treated by five different WPTA clinicians in three recruiting localities.

6.2.1 Hospital participants

Twenty-four people were approached by their treating clinicians to participate in the study. Of those, 14 people agreed to be contacted. I was able to reach 11, all of whom

agreed to take part. Ten were interviewed, as one was not available at the time the interviews took place. To protect participants' identities, where a diagnostic label could risk identifying the person, a global description is provided here. Four participants identified themselves as New Zealand European, one as Samoan, one as Māori, one as European and three as South African. Table 2 details further characteristics of the hospital participants.

Table 2

Key Demographic Details for Hospital Participants

Pseudonym	Age at the time of the interview	Illness description and duration	Impact on life prior to being seen by the WPTA clinician according to the participant.
Jason	29	Urticaria; 13 years	Physically restrictive.
Claire	24	Rare autoimmune illness symptoms 10 years	High impact both in terms of impact on her life but also in the quest to find out what was wrong.
Ian	62	Autoimmune illness; 10 years	Symptoms so severe that he had to stop work, restricted social life.
Jonah	39	Food intolerances; over 10 years	General discomfort and lack of energy.
Ben	20	Severe asthma, allergies and eczema; from a few months old	Lengthy hospitalisations, not able to participate in childhood social activities, ongoing interactions with specialists. Life revolving around the illness.
Steve	60	Attacks suspected to be food-related; less than a year	Frightening when they occur.
Beth	51	Severe asthma, allergies and eczema; over 30 years	Ongoing, nearly monthly hospitalisation for asthma, very restricted physical activity and mobility.
Amy	35	Unexplained and severe episodic pain; 5 years	Had to stop training, ongoing interactions with the health system. Living a restricted life with fear of attacks.
Lorie	51	A rare autoimmune disorder; about 2 years	Severe impact on life, having to change employment arrangements, ongoing tests and treatments.
David	35	Urticaria; months	Uncomfortable, distracting and painful, also embarrassing because of impact on appearance.

6.2.2 Physiotherapy clinic participants

Two recruiting physiotherapists approached 12 people in total and nine agreed to be contacted. I was able to reach all nine, and they all agreed to take part. Eight were eventually interviewed, as one was not available at the time the interviews took place. Six of the participants identified themselves as New Zealand European, one as European Māori and one as South African. Further details of these participants are presented in Table 3 below. I chose to present all the participants from the two different physiotherapy clinics together to help maintain their anonymity.

Table 3

Key Demographic Details for Physiotherapy Clinic Participants

Pseudonym	Age at the time of the interview	Illness description and duration	Impact on life prior to being seen by the WPTA clinician according to the participant.
Jane	37	Joint and muscle pain; a few months	Physically restrictive and uncomfortable.
Pauline	24	Severe pelvic pain episodes and fatigue; 1 year	High impact both in terms of ability to engage in studies and in the quest to find out what was “wrong”.
Dan	48	Depression, anxiety; a number of years	Impact on social participation and wellbeing.
Valery	45	Severe chronic pelvic pain; 30 years	Significant pain and bleeding, impact on career and life.
Colleen	47	Movement disorder; from birth	Lengthy hospitalisation, restricted mobility, emotional distress, ongoing interactions with the medical world.
Greg	71	Post operation pain; 18 months	Debilitating pain had to wake up at night and take around the clock pain medication.
Cathrine	50	Joint and muscle pain; 6 months	Was waking up at night and stopped her from living her life as she is used to.
Kathy	86	Chronic joint and muscle pain; years	Needed a walking stick and to call ambulances to take care of her pain.

6.3 Key themes

In making decisions on how to communicate the findings, I tried to remain cognisant of my research question and organise this chapter in such a way that would answer the question and remain grounded in the methods and the data. The research question was purposefully constructed to comprise two distinct parts. The first part pertains to the analytical endeavour, *“What can be learned from an in-depth consideration of the experience of persons treated in the WPTA for their chronic conditions...”* The second part deliberately brings to the forefront the intended application of these findings: *“... that could be of general relevance to improving the mainstream care approach of chronic conditions?”*

The findings presented below are organised around the four themes and 14 associated sub-themes. To aid the readers’ navigation, each section begins with a figure outlining the theme, and the sub-themes from which it was constructed, followed by an in-depth discussion with reference to supporting data.

After reviewing the different approaches one might adopt in reporting on qualitative findings, (Cutcliffe & Harder, 2009; Sandelowski, 1998; Sandelowski & Leeman, 2012; Thorne, 2008), I chose to initially present my themes in a sentence form. This is done with the purpose of offering the reader an overview, before focusing on the description and interpretation of each theme separately (Sandelowski & Leeman, 2012).

The four overarching themes are articulated below:

- For patients to be willing to enter and engage in the WPTA relationship, or any meaningful therapeutic relationships, they may need to feel **seen as persons, and feel explicitly acknowledged for their unique illness history.**
- Patients appeared more likely to engage in the therapeutic relationship when **clinicians bring their whole selves into the therapeutic encounter.**
- Because the WPTA in the context of this research is encountered in a dualistic mainstream setting, it is often experienced as a “shock” by patients. **Negotiating the first encounters** in this context may underscore the success of the treatment.
- Patients/persons describe the WPTA as providing them with a profound and transformative educational experience, which they conceptualise as a “**door into understanding**”: they highly value the awareness, and subsequent insight into ways to practise greater control over their symptoms. Understanding the mind-body connectivity appears to result in them experiencing freedom from their conditions and their symptoms.

An overview of these four themes and associated 14 sub-themes are presented below in Figure 3.

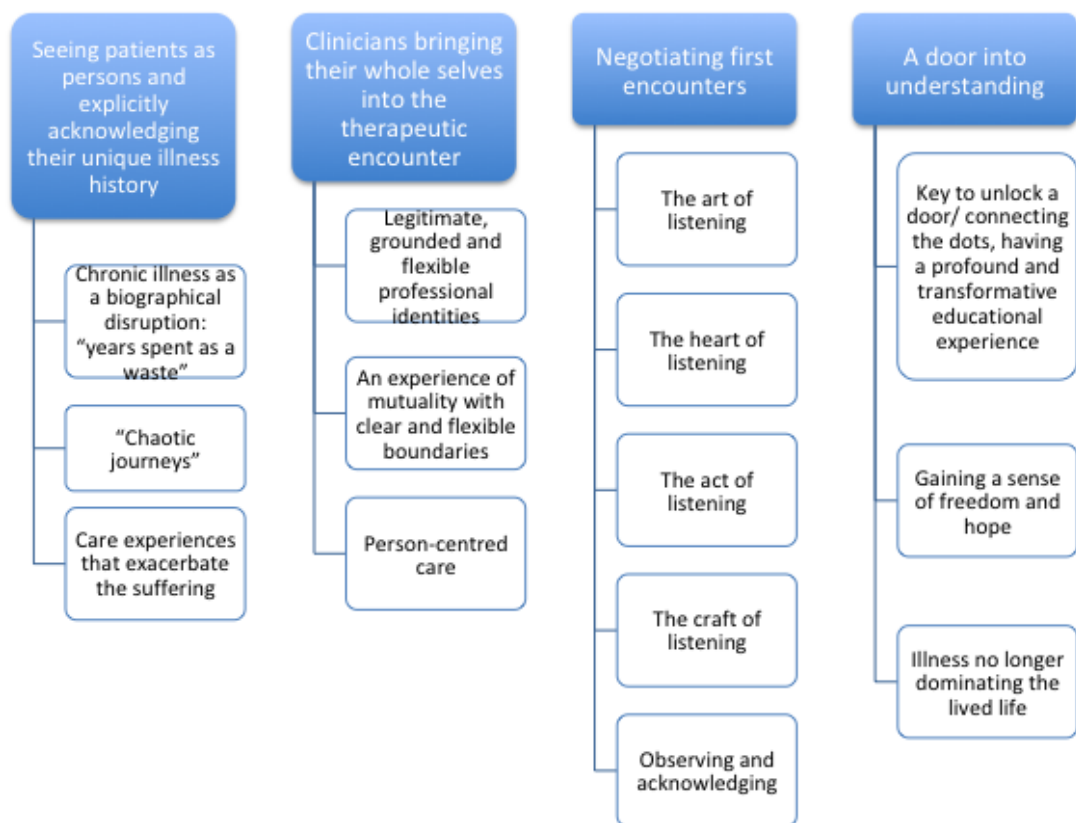


Figure 3. Overarching themes and related sub-themes.

6.3.1 A note about the ways by which identities were disguised in using quotes to illustrate themes

Wherever the illness was highly unusual, and therefore identifiable, the illness is not specified to ensure the privacy of participants is maintained. The same principle was practised when the details of the person could be identified from “their story” as presented here. Because all but one of the clinicians in the primary research were women, all the clinicians are described as “she or her” to help protect the identities of both the clinicians and the participants. However, the secondary analysis included people who were seen by a single male clinician and he is referred to as such. Finally, in the hospital, the three clinicians who practise WPTA have different professional identities, and therefore are all referred to as “WPTA hospital clinician” to ensure once more, that their own identity, as well as that of the participants, remains anonymous and confidential.

6.4 Theme one: Seeing patients as persons and explicitly acknowledging their unique illness history

Figure 4 provides an overview of theme one, along with three related sub-themes from which it was constructed. Each of these is discussed in more depth below with reference to supporting data.

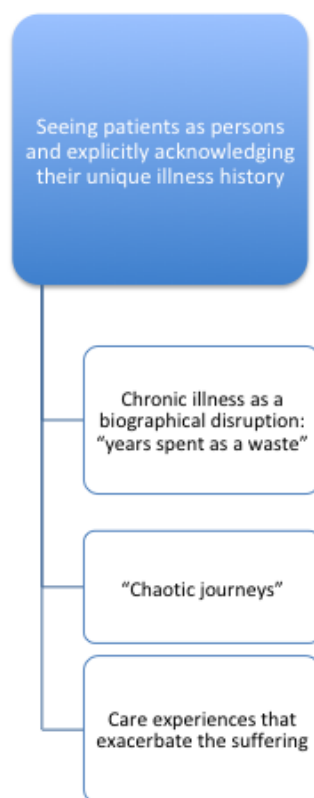


Figure 4. Overview of theme one and the three related sub-themes from which it was constructed.

What does it mean to be seen as a person? The timelining method created the space for participants to tell their history in the ways they chose to tell it. Indeed, throughout the research, participants deliberately communicated the impact their illness and associated symptoms had had on their lives. Despite not being asked explicitly about their physical symptoms during the urticaria study (Lindsay et al., 2015), where I conducted the secondary analysis on the original audio recorded interviews and transcripts, interviewees took time to articulate the disruption these created in their lives. They elaborated on the disruption the symptoms caused, from a day-to-day perspective and, more fundamentally, how the illness impacted on their sense of who they are.

And not knowing why. It is the not knowing why, the not knowing when it is going to happen because it didn't. You never knew when it was going to happen because I didn't know what my triggers were as to what was causing it to come on and then of course it can, you know, you get it on the Monday and I'm screwed for three days. There are times when I literally cannot come to work for three days because I can't get my shoes on and I can't walk. (Second patient, first interview, Urticaria study, from the secondary analysis phase).

In quite a few of the descriptions given, it appeared as if living with these symptoms had almost altered the very essence of who they thought they were. Throughout the primary research, participants communicated how the ways they saw themselves had fundamentally changed. For many, their sense of self transitioned from healthy and capable, to becoming dominated by unpredictable symptoms. This resulted in their lives being altered in some crucial way:

But since then [symptoms onset] I have been, like for months afterwards I was at the point where most days I couldn't attend university. I went from being an entirely A grade student to getting a C, you know like Cs; because I couldn't attend university anymore, I was in a huge amount of pain. My relationship at the time suffered, I was feeling, like, helpless. Because no one knew what was wrong. (Pauline)

Participants communicated the impact that ongoing encounters with the health systems and clinicians had, in-and-of-themselves, materially disrupted their lives and how they saw themselves. The following extract echoes many of the interviews:

So from that November attack I started to go, "I need to investigate this hard and find out." And it took nearly three years to get the investigations that I

needed. They kept finding nothing, and every time I'd have blood tests, they'd say, "Oh, we have just got to do it in order to... We will just check for this, gotta see if it's this. Just do this first, just do this first." I'm like, in the meantime my life was on hold [...] I was missing school, I just wouldn't leave the house. And I would live in fear. (Amy)

This extract illustrates the importance participants placed on being acknowledged for the impact these medical encounters had had on their lives as a consequence of the illness.

The WPTA clinician views all illness aetiology as non-dualistic and as such will invite the person to tell their life's emotional, relational and even spiritual story in the clinical encounter (Broom & Joyce, 2013). However, for the person being treated for physical symptoms, their life's story is now entangled with the story of their illness and the quest to treat it. The analysis suggests participants placed an importance on being able to communicate to their treating clinicians the impact the symptoms and encounters with the health system had had on the ways they lived their lives. In addition, the analysis suggests that the experiences participants had had with the medical system may, in fact, have increased their emotional as well as physical distress.

Therefore, the experience with any clinician that explicitly acknowledged their illness history, including their experiences with the medical system, may have been experienced as healing. This explicit acknowledgment of their unique life story as well as illness history became a foreground on which stronger therapeutic relationships could be established and other aspects could be explored. The analysis revealed that the act of attending to the ways their illness had affected their lives in a compassionate and empathetic manner was interpreted as indicating that this clinician would be doing something different and was truly interested in them as a person. When this acknowledgment was not sufficiently present in the WPTA, patients appeared less likely to engage with the clinician.

Participants often spontaneously contrasted experiences where they felt acknowledged for the impact illness had had on their lives, with experiences when they felt they were not. The following extract illustrates where the participants contrasted the WPTA clinician in the immunology department with a previous clinician he had seen in the same department:

But also probably her manner, it was more sympathetic than perhaps [Jane] who was more cold if you can call it that. [Jane] was very good but you were a patient. Whereas I think with [June] you feel that you are a patient but you [the patient] are concerned. She is emotionally involved as well. Whereas with [Jane] she was never emotionally involved. And I think that develops that response or that, that doesn't develop the trust in itself but it develops the what's the right word? It enhances the relationship anyway. (Ian)

On further exploration of what he meant, Ian explained that the WPTA clinician seemed to care about him as a person, whereas the previous clinician appeared to be primarily focused on the investigative process of finding a clear aetiology for his illness.

According to Ian, because the WPTA clinician seemed to care about him as a person, he was willing to go along with the WPTA.

This desire to have the illness history acknowledged and heard by the treating physician or medical practitioner was particularly vivid in one of the interviews, where Amy, who suffered from “unexplained” symptoms, described how she wrote her own referral letters as the condition worsened: *“I actually wrote a letter to [previous specialist] prior to going in, with an overview, because he was one of the last people I saw before I saw [hospital WPTA]. So they both got a nice little packaged overview of my condition, like a referral letter but from my point of view”*. Amy used descriptions such as, *“I feel like they saw me as a person, they didn't just see my condition”* to explain how she felt these two medical professionals interacted with her. She attributed this experience as related to her sending her own referral letter, which she felt directed their attention to her as a person and contextualised her experiences with her symptoms.

As noted in Chapters 1 and 5, one of the synthesising concepts used to guide the questioning of the data was concerned with how important it was for patients to be “ready” to enter the psychotherapeutically influenced WPTA (Chapter 1, Section 1.3). Through engaging with the data in reflecting on this question, I came to transform it. My question became, “What is it that the patient needs from the clinician to help them believe that they will be treated as a whole person?” WPTA clinicians who practise in a psychotherapy-influenced way, it can be argued, may see this being achieved by their deliberate and careful attendance to the patient's “other story” (Broom, 1997). However, the importance of the illness context itself may be underestimated.

The participants in the current study experienced physical symptoms, which had had significant and, at times, detrimental impact on their ability to live their day-to-day lives. The analysis suggested that before patients may be willing to share their “other stories”, they were looking for the clinician to listen to, and acknowledge, the severity and impact of their physical symptoms, as well as previous experiences with the medical system on their lives. A man with severe urticaria tried to explain this to me in one of the earlier interviews when describing his reaction to encountering the hospital WPTA clinician for the very first time, *“So when I walked out of the room I was kind of like, ‘Oh, I still feel what I am trying to say, I haven’t been able to get it all out.’”*

It was revealed later in the interview that he found the WPTA difficult to accept at first, when he was not able to get across his story of ill health and the impact it had had on his life, because he felt that the clinician was more interested in his relational and emotional stories. This perceived focus resulted in him feeling not truly seen as a whole person. He described feeling this way despite later on having (by his own account) a very successful WPTA psychotherapeutic experience.

Indeed, ongoing examination and analysis of the interviews revealed how central it was for the person being treated that their “illness story” was welcomed into the clinical encounter. The centrality of this theme became clear through ongoing exploration of three sub-themes, which were constructed and examined throughout the analytical process. For the person being treated, the chronic illness in itself can be experienced as “years spent as a waste”, a type of biographical disruption where they could not live their life to the fullest because of the impact of the illness and the symptoms on their day-to-day lives. For some, these disruptions resulted in altering the ways in which they saw themselves as people. Participants often endured very “chaotic journeys” in the health system, further complicating and disrupting their lives; and in the process, they encountered care experiences that exacerbated their physical as well as emotional suffering. Patients bring all of these experiences with them into the clinical space and the WPTA encounter.

6.4.1 “Years spent almost as a waste”: A type of a biographical disruption

Throughout this study, the illness seemed to define the sense of self of those participants with more severe chronic symptoms – the “thing” that defined them in how they saw themselves and related to others. It appeared to have been especially the case before the participants engaged in the WPTA experience. The timelining method

provided the space for participants to articulate the impact their illness had on their lives.

Ian was diagnosed later in life with an immunological condition, after many years of experiencing unpredictable symptoms. He described the experience of being “defined” by his symptoms prior to engaging in the WPTA:

I think in the first 5 years or 6 years my entire focus was on the body side. And you don't really cope with that because it's happening. Well, you cope physically with your day-to-day life. But you don't, it dominates your life put it that way. And it dominates what you do and what you think and what you read and everything. And what you talk about.

The illness changed the ways in which participants viewed themselves, their experiences with other people and how they lived their lives. The analysis suggested that for patients to feel as if they are treated as persons and seen as a whole, clinicians needed to attend to the impact of the physical symptoms on their lives. This was true for all clinicians, irrespective of the “banner” they practised under.

The symptoms disrupted the lives of all the participants across the data sets. In the primary study, participants such as Beth had to be hospitalised regularly for her condition: *“I would at one stage have been going into hospital in (home town) once a month and most of those would be ICU first.”* Others experienced devastating side effects like significant weight gain because of the medication and were constantly going up and down in medication dose, which had a severe impact on them: *“I went up to 144 kilograms at one stage. And I was on high dose prednisone then I would come down to about 15 milligrams per day and then I would go back up when I flared up and then I would come down. So it was really up and down all the time.”* (Ian)

Others still, had such severe symptoms that they seem to have come to almost dominate them. An illustration of this can be seen in Amy’s interview - she suffered from unexplained pain episodes. For her, the fear of the symptoms meant that she *“started to catastrophise it and have fear avoidance kind of behaviours around it [...] I couldn't be driving a car on the motorway when this [pain episode] started, because this would be dangerous... .”*

6.4.2 “Chaotic journeys”

Throughout the interviews, patients communicated a sense of feeling lost, confused, and being handled like a “product” moving through the “production line” in the medical system. Most participants spent a fair share of their time going to different appointments, undergoing investigations and hospitalisations in trying to get resolution for their symptoms. Amy described the time, money and effort she spent in trying to get “an answer” for her episodes of pain:

And I got shifted around practitioners and doctors and if it didn't fit into their box, I got moved onto the next person who didn't take into consideration what had happened in the previous place, and I just felt lost in the system, and it totally affected my life last year to the point that I took two months off. Not because the condition was so severe that it made me sick, it was the stress around the condition, and I needed to take time off to push for some answers or some help properly.

As illustrated in Amy's quote, participants often described what appeared to be a medical quest to find a single aetiology. Many of the people interviewed spent significant amounts of time (and money) in and out of hospitals, private specialists and other clinicians. For example, Claire, who had suffered from “difficult to diagnose” symptoms, had spent the majority of her time in the previous months in and out of different hospitals in the Auckland region:

So I saw the doctors, ophthalmologists, I think they are called at [names hospital]. And it was a bit of a chaotic journey shall we say. At first someone thought I had possibly toxoplasmosis from my cat, [then] that was ruled out. Then, I saw another doctor who thought I had something called X disease, ... it's an autoimmune disorder. And then I saw [names doctor] who thought I may have something called Y, which involves the eyes and kidneys. And then all the doctors had a discussion apparently, and ran lots and lots of different tests. So I went to the hospital and back, I have been there about 12 times now, within the course of two months. (Claire)

These transactions in the health system could be seen as adding to participants' distress and sense of biographical disruption, in terms of actual time, money and effort taken to find a resolution/answer/way forward for their symptoms. In addition, these interactions

were also described in terms of their emotional impact as so many of these were described as difficult and negative.

The data suggest a medical system that is designed and geared towards a certain type of illness – one with a clear and observable aetiology. For people who suffer from multiple symptoms, which take time to diagnose or are not able to be diagnosed, the biographical disruption seems to have been enhanced. For example, Pauline, who suffered from episodes of chronic pain, described how her GP did not believe the severity of her pain because “nothing was seen under the microscope”, that is, she could not find a clear aetiology for the pain and consequently refused to give Pauline pain medication, because she (the GP) did not think the pain was real. As a consequence, Pauline had to endure the following;

But she [the GP] was like, “Well, I am not going to prescribe that [pain medication] to you because I still don’t think that you need it.” And it was horrible to hear her say that because obviously, like they gave me tramadol after the surgery. So you know I only had a limited amount in the first place, [and] I got to the point where I was picking pain medication out of vomit. So I wouldn’t be wasting it because I knew that she [the GP] wasn’t going to be prescribing it to me again.

Pauline, an articulate young woman, came to doubt herself because of these interactions. *“When the GP said it [how the pain was not real because nothing was found in an investigation] I took it as an attack, and one of the main things that my mind leapt to is, ‘Oh, she thinks I’m crazy’ and that’s just been such an innate fear, that I shut down.”* Pauline disclosed how she ended up “wishing” she could get a diagnosis, even if that meant painful surgery, so that she would be taken seriously by her treating GP.

Descriptions of chaotic journeys and problematic interactions were prevalent throughout the data. This was the health system context in which most of the participants had come to encounter the WPTA clinician. Specifically, in the hospital setting, the physical context was virtually identical and they described coming in expecting to get more of the same, and experiencing something quite different. Beth, who was referred to the immunology department for her chronic asthma condition, described this as:

Well, I assumed, in my ignorance, that she would be a bit more like all other doctors I had seen, you know check the nose, check the chest, do all the normal

questions and all those sorts of things. She was very relaxed, made me feel relaxed. And was just generally really good, you know. It wasn't like going into some specialist and you sit there, and you get agitated, and anxious all the way through, you know.

The analysis suggests that attending to their previous experiences with the medical system, and other medical practitioners, may be an important part of the process of laying the ground for patients to engage in the rather intimate WPTA care experience. Colleen's encounter illustrates this point. Colleen suffered from a movement disorder from birth. She was subjected to numerous surgical interventions and was very apprehensive about seeing a physiotherapist. She described how the physiotherapist, acknowledging how hard it must have been for her to be left in the hospital by her parents, specifically used a visualisation breathing exercise in this context. As a consequence, Colleen described that encounter with the WPTA physiotherapist as:

There wasn't intrusiveness, there wasn't inappropriate questions. There wasn't categorisation, there wasn't labelling. There wasn't, there was a carefulness and respect, and a reverence for who I presented as, what I presented as, what my body presented as.

6.4.3 Care experiences that exacerbate the suffering

As the previous sub-theme illustrates, participants described having to navigate the complex medical *system*. On top of that, many described care experiences that spoke of clinicians whose approach to care could be described as *condition and expertise centred*. They spoke of treatment experiences delivered by professionals, who appeared *stuck* in their professional identities, speaking to patients using overly medical and opaque jargon, and focusing only on those symptoms which fell under their own expertise. These encounters may have exacerbated the patients' suffering, as exemplified in the following quote from Claire:

They [doctors] are throwing at us all this medical jargon, just stop and just think; not everyone can understand what's going on [...] Approach us like we are not a product, we are not just a file on your desk, next, next, next which I felt with some of the doctors I saw. I felt like I was just being pushed through, "Hurry up, I want to go home" sort of thing, for them.

Ben, who had extensive experience with the medical system from an early age, commented throughout his interview on how different doctors "*were pretty set in their*

own way” and gave specific examples such as relaying how one specialist “pretty much that’s all she wanted to do, was just put me on this medication, that we necessarily didn’t want to do. She didn’t really provide me, with like, avenues of working around it.”

These experiences differed by the degrees to which the condition was easy to diagnose, or whether there was a diagnosis. For people with more severe and harder to diagnose conditions, the at times humiliating and de-humanising experiences with “mainstream” clinicians appeared to have exacerbated the suffering. This was especially present with two of the participants who experienced painful and undiagnosed episodes, one seen in the immunology department and another by a WPTA physiotherapist. Pauline, who ended up in the emergency department for her pain, described a humiliating experience of being dismissed by the nurse in that department:

Well, there’s another time when I went to A&E because the pain was so bad, I couldn’t breathe properly. I was in the consulting room with him [triage nurse], and he said, “What’s happened?” And I said, “I have got a chronic problem with pain and I have been told to come back if it gets really bad, if I get more chest pain. So I came back.” And the first thing he said was, “The emergency department is for emergencies, and chronic illnesses are not emergencies.” And you know, like it was a horrible experience, and I was sitting in the waiting room and they told me they were going to give me pain medication, and it was like an hour and a half later, and I still hadn’t been given any, and it was just [pause], I got home and I was totally drained.

Inevitably, these experiences were at the forefront of the patients’ minds when entering any clinical encounter, and in some cases were used as a reference point from which they assessed the WPTA clinician and the associated therapeutic experience. Moreover, just as with other traumatic life events, such as physical and sexual abuse, the experience of the medical system, in-and-of-itself, was perceived by the participant as abusive in some cases because of the physical and emotional pain the treatments have caused them.

Colleen was born with a chronic and permanent disorder which impacted her movement and posture and inevitably how she lived her life. In her childhood, she was subjected to numerous medical procedures trying to correct her posture. She described how she brought these experiences to the first encounter with the WPTA physiotherapist: “And

when I think of my time in hospital, there is a sense of lying on the table with my legs scrabbling to get away. And my memories of being spoken over, talked about as if I wasn't there, talked about and described in terms of a body part, or a muscle that wasn't working."

Colleen specifically chose the WPTA physiotherapist, as she believed her approach may be different and could help her deal with regression in her physical ability, as a consequence of a fall. *"And I was experiencing panic attacks [as a consequence of the fall] and just an inability to deal with stress and cope. And so, I really had to go inward. And I came to see [WPTA physiotherapist] because it felt right."*

In summary, theme one captured the importance, from the perspective of participants, of feeling acknowledged as persons first. This included feeling acknowledged for the aspects relating to their illness experience, the symptoms and care they had had before encountering the WPTA clinician for the first time. It highlighted that each person arrives at the consulting room with a gamut of previous experiences in the medical system, which they use as a reference point. It has also highlighted the apparent importance of the clinician's ability/willingness to acknowledge the illness as a biographical disruption for the person, and how participants' previous experiences in the health system may have exacerbated their suffering and become part of their illness experience in-and-of-themselves.

6.5 Theme two: Clinicians bringing their whole selves into the therapeutic encounter

Figure 5 provides an overview of theme two, along with the three related sub-themes. Each of these is discussed in more depth below with reference to supporting data.

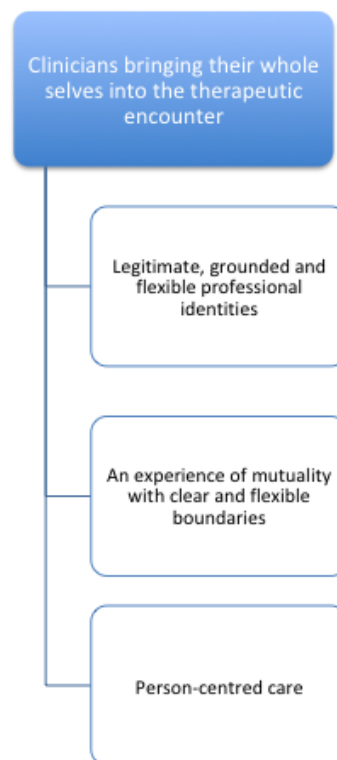


Figure 5. Overview of theme two and the three sub-themes from which it was constructed.

As outlined above, it appeared that clinicians who were experienced as having rigid professional identities and boundaries had the potential to exacerbate suffering. Initially, I experimented with a theme concerning this observation as “condition and expertise centred care”. However, after ongoing reflection and engagement with the data, this theme seemed to be an insufficient articulation of the impact that rigid and heavily boundaried care appeared to have on patients.

In the WPTA, patients are invited to bring their whole selves, to disclose private and often painful information about themselves to their health professional. Furthermore, in the context of a hospital, they are asked to do so in biomedical settings where they are not expecting this kind of relationship. In this context, experiencing clinicians as allowing *their* whole, authentic and appropriate self to be present in the clinical encounter appeared critical for patients to do so themselves. This was the difference between experiencing care with experts who appeared to see themselves as experts first and foremost, and experiencing clinicians who appeared to see themselves as people first with relevant clinical skills. The latter were described as bringing clinicians’ humanness into the encounter, and appearing to treat their patients on a person-to-person level before they drew on their relevant clinical expertise.

This was expressed in the following extract where the person reflected on his relationship with the hospital WPTA clinician: *“It was almost like we were peers in a way. Which is very important to me. Because often times I find that doctors think that because they are doctors, they are so much better than other people, and you know all that sense that ‘We have all this knowledge’”(David).* Similarly, the following extract, from a participant who saw a WPTA physiotherapist, articulates that a distinguishing feature between her WPTA clinician and another clinician was the way in which the WPTA clinician disclosed personal information about herself, creating a shared space within the encounter: *“She relates a lot of things to herself, whereas a [names another type of clinician] never talks of themselves. In a meeting with them, they will always talk about you. She talks about her own family. She will bring up her daughter, she will bring up her mum. You know, we will chat about a walk that she’s done. So you don’t feel like you are there and I am here, so you both are having a conversation”* (Jane). This was also demonstrated in how Catherine thought of her WPTA physiotherapist: *“I felt like she had me, she considered me in her day-to-day life rather than – I had been and gone and the money had been paid – and she dealt with me. I felt like she was including me in her thoughts.”*

Indeed, this understanding was obtained through separately analysing the interview scripts of participants who worked with WPTA physiotherapists. I came to identify the ability of clinicians to bring their whole selves appropriately into the clinical encounter as a necessary ingredient for the person being treated to truly experience whole person-centred care. Clinicians’ ability and willingness to bring their whole selves into the clinical encounter appeared to have had positive and healing impact on participants in all clinical contexts, whether it was within the WPTA or not.

The participants appeared to sense, regardless of the level of formal education, age or ethnicity, whether or not their clinicians were prepared to bring more of themselves into the clinical encounter than their professionally prescribed identity and clinical skills. This is demonstrated in the following quote from Catherine, who was seen by a WPTA physiotherapist:

And I guess I appreciate the fact that I wasn’t just a number walking into her room. I was a person and she had given me thought, and considered me, and what I required, and what I needed, and what issues I had. And that very thing, of somebody caring about you, makes you feel more closer to them. It makes you feel more open to sharing.

This in turn, appeared to influence the ways in which the patient was prepared to share their whole self with the clinician; that is, becoming willing to engage in the care relationship. This analysis has contributed to my reframing questions regarding patient readiness to focusing on the clinicians' practice, which may facilitate or even activate that readiness. As outlined previously, this analysis led me to question what it is that the patient needs from the clinician to signal for them to believe that they will be treated as a "whole person".

In deliberately selecting quotes for Emily's story, I tried to convey what participants were observing and noticing in their clinicians which signalled to them something different about the experience. This was often described in contrast to other experiences. Similar to the previous quote, where the person felt it was "*like we were peers in a way*", the following extract illustrates the deliberate and careful ways patients made these assessments.

I felt like she really listened to me, she didn't just throw questions at me like a lot of previous people I have seen did... She's not intimidating, she's not sort of sitting there legs crossed just you know, ... her mannerisms and the way about her made me feel very comfortable, as opposed to some other people who I have seen, who seem very, you know, like I'm just another product.

Clinicians' ability to bring their whole selves into the encounter was evident in most of the participants' accounts regarding the WPTA, but was not unique to them. I suggest that it is more likely to happen with WPTA clinicians because of their conceptualisation of illness aetiology, which may influence this willingness to be a person in a relationship with the person they are treating. Participants experienced this in subtle ways, such as when clinicians asked for their input, reflected on something they said in a previous visit, and shared some personal information.

Colleen explained how because the WPTA physiotherapist shared with her that "*she had had hospital experiences as a child*", this was what signalled to Colleen that this indeed would be a different clinical experience. To Colleen, this willingness to share something private and personal was crucial and "*it was the key that I needed*". Colleen went on to describe the encounter: "*There was a freedom in the room; I think there was a clipboard but it wasn't obvious.*" And how this way of being by the WPTA physiotherapist had resulted in her "*being scared to speak but doing it anyway*" because of that "*feeling of being allowed*".

When trying to articulate what the relationship felt like, participants used descriptions such as, “*like a friend, but not a friend*”. The relationship felt more personal to them, but they were well aware it was not a “real” friendship. That willingness to encounter them, as human-to human, was what participants took from the experience on a relational level. Catherine went to see a WPTA physiotherapist for severe pain. She saw her a number of times and described herself as now being 90% pain free. When I asked how she might explain what seeing the WPTA physiotherapist was like she answered:

I guess I would explain to them that she is a professional but a friend. I mean I know she's not my friend, I don't invite her over for a cup of tea or anything. And she doesn't say, "Come over and have a piece of cake." But I still feel that she is still in my circle of friends. A friend that I pay to go to see. I would explain it more like she is in my circle of people that mean special things to me, and she is part of that.

This overarching theme was constructed through ongoing exploration of three sub-themes. These are discussed in more detail below.

Clinicians who bring their whole selves into the medical encounter are experienced as having well-grounded, legitimate and flexible professional identities. They are trusted clinicians with specific specialities which are the reasons the participants chose to, or were referred to, see them. The trust is initially based on the participants' confidence in this professional identity. However, the clinicians approach the person in front of them as an expert in their own illness, a person with a story to tell who should be listened to. Therefore, the relationship is experienced as mutual with clear yet flexible boundaries. The person knows the clinician is not their friend, but they feel that they are “on their side” and that they are both working together to achieve an outcome, rather than the clinician having all the answers and it being up to the patient to “obey and follow”. This is the background which contributed to the participants feeling they had encountered person-centred care, where the clinicians treated them, not the disease or the condition.

6.5.1 Well-grounded, legitimate and flexible professional identities

Participants who were interviewed in the primary research engaged with the WPTA clinicians because of their professional identities, both in the hospital and with the physiotherapists. In the hospital, patients were mostly referred to the WPTA clinicians

as they would have been to any other clinician in this setting. Those who were treated by physiotherapists also sought them for their clinical expertise.

The data suggest that these professional identities were important to participants. It appeared from the stories shared by participants that the experience felt more grounded because of these professional identities. This is especially evident in the following extract from Valerie's interview: *"There's like a credibility, I think, which makes you walk through the door [because she is a physio]. ... I think it provides you, well, a comfort. Yeah, I think that's the way I would describe it, a comfort that she knows what she is doing."*

Nonetheless, participants commented on positive experiences with all clinicians who were flexible and who showed willingness to try different things. These included alternative approaches, which might help the participants – even if they felt “outside” the clinician's prescribed professional identity. To participants, professionally trained clinicians who *"as much as they were [experts] in their field, and specialists, they still kind of had that open mind"* and *"approach this [condition] from multiple ways"*, appeared to have demonstrated that they genuinely cared for the participants because they wanted what was best for them—not only what they felt comfortable with professionally. Furthermore, this willingness by professionally trained clinicians to remain open to ideas, including those of the patients, was seen as a sign of humanity and even humility, signalling a willingness to acknowledge the expertise of the patient in their own condition, as this quote from David suggests:

Yeah, I think everyone should always be willing to try new ideas. Especially if the ideas have some sort of track record of effectiveness. ... You know there is a certain amount of humanity needed to go for the sort of holistic approach. Because you can give advice, but you also need to be able to step back, and let the patient be in charge, and to kind of control their own sort of attempts to fixing things.

A clinician's ability to admit when they might not have an answer, without blaming the person for having an illness that cannot be explained, was interpreted as a demonstration of humanness and humility. This was further experienced as the clinician's ability to bring their whole self into the encounter as a person, rather than as a “know it all” clinician. Amy, who had extremely painful and idiosyncratic “attacks”

for which there was no clear aetiology, reflected on her positive encounters with a number of clinicians (who were not WPTA) who tried to help her:

I think if I compare to the four main people, who I think of the most thorough this experience, is from [Hospital WPTA] approach compared to say like the good [one type of specialist] and the good [other type of specialist], who I feel were, as much as they were in their field and specialists, they still kind of had that open mind that, “I have never heard of this before”. They were honest. They were honest at their lack of ability to figure it out for me. And that they would help me as much as they can. They reassured me that they would make sure someone was looking after me and, [that] if they can’t find it, [they] won’t stop looking...

Amy experienced these encounters as comforting and healing in-and-of-themselves, especially in contrast with clinicians who did not believe her and with whom the interactions exacerbated her sense of loss and even suffering. Prior to encountering the WPTA clinician, Amy “*got shifted around practitioners and doctors. And if it didn’t fit into their box, I got moved onto the next person who didn’t take into consideration what had happened in the previous place. And I just felt lost in the system and it totally affected my life last year.*” It was precisely because of their clinical and professional expertise that this ability to demonstrate humility and humanity was so important and validating for participants like Amy.

The professional expertise of the WPTA clinician was important for participants. They seemed to have highly valued the combination of being treated as whole people by medically trained clinicians that related to them on this human-to-human level while drawing on their professional expertise. A participant with experience with mental health professionals reflected on his experience of working with the hospital WPTA on his chronic urticaria:

So with [hospital WPTA] there wasn’t that kind of psychotherapist bond that you usually get. You know, where this person becomes a confidant. But it was, so it was similar in that she was asking the same kinds of questions, but I didn’t feel the need to go into as much depth as I would, and it was more targeted as opposed to broader “How are you feeling today?” It wasn’t one of those, it was more sort of quite specific to sort of things that you’d kind of discussed and then had marked already as useful indicators towards the symptoms. (David)

David recognised that the WPTA has its roots in psychotherapy, but reflected that it was a qualitatively different experience as it focused on his symptoms, rather than more broadly on his life. This was something he found helpful and reassuring in the context of dealing with his chronic illness.

It was important for participants in the primary study that their treating clinicians had the relevant clinical expertise for the chronic condition they suffered from, be it as an immunologist, dietician or physiotherapist. The presence of this clinical expertise as a grounding yet flexible element in the therapeutic encounter was particularly evident in the accounts of participants who saw WPTA physiotherapists. Jane, who went to see a WPTA physiotherapist for chronic pain, was very deliberate in how she articulated that.

For me a physio... it was important [that she was a physio] because they obviously know the mechanics behind what's going on with the body when you do breathe like that. So, not only are they trained in traditional, well you know conventional medicine and in physiotherapy, but they have actually been intrigued enough by the not-so-conventional stuff to go into that, and incorporate that into their practice, with that background foundation, academic training that they have. Academics, training and research. So for me it was important that she had, that she was a qualified physiotherapist. I wouldn't have gone to a massage therapist who had an interest in body-mind.

Indeed, the importance of the professional identity and clinical expertise in this context was underscored in the secondary analysis as well. In some cases, this was an important element of patients' willingness to "enter the process". This was first evident during the secondary analysis of the video project (Cunningham, 2015) where participants chose to see the private clinician. All of the videoed women engaged with the private clinician on the basis that he was a trained physician as well as a psychotherapist. This was an important "entry" point to the therapeutic relationship as demonstrated by the following quote from one of the videoed women:

...but at the same time, I knew that he had expertise in the traditional sort of medical type stuff as well. Which I don't know... I guess looking back, I sort of had faith in the fact that he had both, expertise in both sort of areas yeah. He was coming at it from a different angle but he also had the other, you know? I didn't feel like he was a quack in any way, or anything like that.

6.5.2 An experience of mutuality with clear and flexible boundaries

Clinicians' ability to build a clinical relationship which was built on their professional expertise, and yet flexible enough to accommodate the persons' own wishes and desires, contributed to a sense of mutuality. I deliberately chose the word "mutuality" rather than its synonym of reciprocity. The word mutuality speaks to the intimacy, the emotional, relational aspects of the encounter, whereas reciprocity could be construed as inferring a more transactional quality.

This sense of mutuality was facilitated by the clinicians' ability to set clear, yet flexible boundaries in the therapeutic encounter. The notion of professional boundaries kept coming up throughout the interviews. I would suggest that because participants were so well versed in the medical system, many were well aware of the concept of professional boundaries. These participants reflected throughout the interviews on the impact these boundaries had on them, and often contrasted the WPTA with previous experiences. For example, Colleen, in her interview, mentioned boundaries consistently, she reflected how *"it is not allowed [for the clinician to share personal information] in many professional practices, you [the clinician] have to keep your boundaries, you have to keep your space, you have to keep your stuff out of the room"*. Indeed, these boundaries were experienced as barriers, and a sense that the person was on one side, and the clinician was on the other, being spoken to or analysed and perhaps judged. The following extract from Dan illustrates this when reflecting on his experience with mental health professionals.

Because there is necessary boundaries, they are analysing. I guess that I can see their minds ticking over. You know, I know that things are going over in their mind. Yes ok, and I can see it happening because that's their job so they are analysing the whole time. Whereas it's not like a more natural or normal sort of relationship with somebody where it seems to be ... more genuine or authentic.

In the WPTA encounter, the boundaries were mostly experienced positively. They were present, but they were experienced as different, as more flexible and enabling of mutual therapeutic relationships. A number of participants had had experiences with various mental health professionals. In the interviews they spontaneously reflected on the WPTA experience vis-à-vis those experiences. Indeed, Dan who had extensive experience with mental health professionals, spent quite a bit of time trying to articulate the difference in the way he experienced professional boundaries in the context of the WPTA physiotherapy. When reflecting on boundaries in this context, he mused, *"Yeah.*

It's sort of like, ok so I get to talk about it, but stay over there, whereas [WPTA physiotherapy] it is like, there isn't that sort of, the boundaries are completely different."

In exploring Dan's reflections on boundaries and asking him to elaborate on the ways in which the boundaries were different, Dan replied:

Yeah, so the boundary is, you know I thought on the continuum you know she [the WPTA physiotherapist] is further along. There's sort of, how close it's acceptable. And that's quite different to say a doctor who may be actually physically touching you. But that's a completely different feeling... I just wonder if. It's sort of like the difference of being looked at and being seen. So that's one way I sort of think about it... For me it's a, it's kind of like the direction of the energy, let's just call it that for the moment. It's the direction. And it seems like being looked at is, it's all one direction, it's coming in, it's inwards ... and whereas with [WPTA physiotherapist] she is receiving as well. So she is receiving. It's sort of counter to what you would think looking at. But seen, seems to be sort of a two-way thing.

It can be suggested that the issue of boundaries was especially salient in the WPTA physiotherapist encounters, perhaps because emotional intimacy was included in what is essentially a very physical encounter. Arguably, this is quite different to what a person might expect from a physiotherapist. The analysis suggested that the flexible yet clear professional boundaries clinicians demonstrated further grounded the experience. Participants experienced these flexible boundaries as contributing to the sense of safety in the clinical encounter. Jane who suffered chronic pain described this as:

You just feel like you are in with one of your friends having a chat; and that you are two equal people and she's just going to use her expertise to help you out. ... it's like she is going to work with you to help you solve your problem. She is not going to solve your problem for you. Maybe that's the difference with the psychiatrist and the patient, versus her [the WPTA physiotherapist] and her patients.

Towards the end of the interview with Colleen, who suffered from chronic and permanent disorder, which impacted on her movement and posture, Colleen described the WPTA physiotherapist as being able to "see what is not seen, and hear what is not heard". When we explored this further, she too came back to the issue of boundaries,

and how the WPTA physiotherapist was prepared to bring her whole self into the encounter, which deeply resonated with Colleen. The participants appeared to be constantly observing and making their own judgements about whether they would “allow” or “give permission” for the clinician to see them. And whether they would seemed to be heavily reliant on whether they perceived the clinicians to have rigid professional boundaries.

6.5.3 Person-centred care

As outlined in Chapter 2, there is not a universally or even widely accepted definition of what “person-centred care” is (see Section 2.2.2). However, the analysis suggests that when clinicians adapted themselves to the patient in front of them, in how they communicated and approached them, participants experienced this as centred on them. Person-centredness was present in the analysis from the secondary analysis onwards, first as a code in NVivo, then as a theme, and finally as part of a complex question regarding the experience of being treated in a person-centred way.

In the secondary analysis, participants expressed it as an experience of being seen as a person, often for the first time within the health system. Of note were descriptions of the clinician’s openness for them to bring anything they deemed relevant to the consultation process. Participants highly valued that the specialist did not limit themselves to only discussing what was on their charts or medical records. They described feeling “not alone”, “secure”, “safe” and “seen as a person”, which appeared to make them feel willing and able to participate in the therapeutic relationship. This is evident in the following quote from the original transcripts in the secondary analysis:

He [previous specialist] only wants to know about your hives and the itchiness. He doesn't want to know would there be another reason why it has been brought on [...] See I shouldn't say that but it is an impersonal kind of way [...] So it is good to be able to come in, for someone to take on board what else might be happening in your life, and if somebody could put the two together and then say “Well, how about we, you need the antihistamines for a wee while to try and get it under control I guess, but there might be other ways that we can address...”
(Lindsay et al., 2015, third patient after completing her sessions.)

In the primary study, it was also evident, in every interview, that participants felt that being seen as persons, and that the care was for them rather than for their illness, was

important. For example, Claire, the young woman who had a serious and complicated condition, reflected:

So just, [hospital WPTA] didn't look at her watch or anything, I don't even know if she was wearing one, but she didn't look at the time. She was comfortable in her mannerisms. She talked to us like we weren't just product, like we were people, us being my mum and I. And she didn't talk to us like we were other doctors. She talked to us so that we could understand. Not saying that we are dumb, but we don't understand what certain terminology means (laughs). She was good, she was really good.

In the context of the WPTA physiotherapists, the person-centred experience was reflected in participants' descriptions of the physiotherapists' ability to adopt their approach to dealing with quite generic conditions differently, because they accommodated the individual's needs. For example, with some people they focused on breathing, and with others, they focused on understanding their lives' stories rather than following a pre-prescribed protocol for their condition. Jane, who suffered from chronic pain, articulated it like this:

And she [WPTA physiotherapist] will work that into her routine, which is, she doesn't just sit. She doesn't just bring you in and go, "Oh, back pain, let's do the back pain stuff that we do for back pain" you know? She looks at you as a person and thinks, "This is not conventional back pain, this person has other issues going on... breathing, anxiety... whatever". And she [WPTA physiotherapist] incorporates that all into your 45 minutes with her.

In summary, theme two captured the place and importance of professional identities and clinical expertise within the WPTA experience. It described and interpreted the importance, from the perspective of the person being treated, of the clinicians' ability to bring themselves as persons with expertise into the clinical encounter, whether they are WPTA trained or not. This was often contrasted with experiences with clinicians who appeared to see themselves as experts with answers, and did not bring their humanity into the clinical encounter. Clinicians, who can bring themselves as persons first, were experienced as having well-grounded, legitimate and flexible professional identities.

This theme attended to the issue of boundaries within a clinical context as seen and interpreted by the person being treated. It highlighted how clinicians who are able to see the person in front of them as an expert in their own illness, a person with a story to tell

who should be listened to, are experienced as creating a mutual relationship with clear yet flexible boundaries. In this therapeutic experience the patient appeared to feel that the clinician was “on their side” and that they were both working together to achieve a positive health outcome for the patient, following whichever route was most appropriate for them. This experience seemed to result in the person feeling they had been treated as a person and that the care was centred on them.

6.6 Theme three: Negotiating first encounters

Figure 6 provides an overview of theme three, along with the five related sub-themes. Each of these is discussed in more depth below with reference to supporting data.



Figure 6. The relationship between theme three, and the five sub-themes from which it was constructed.

As detailed in the methods chapter, throughout the analysis I used the “story” aspect of the WPTA as one of my sensitising concepts, given the central role the therapeutic content around the “story” plays in the writings regarding the WPTA (Broom, 1997, 2002, 2007) and in my own experience of it (see introduction and Section 2.3.1 for details). Further, one of my supervisors, in his role as thoughtful clinician, regularly questioned my analysis through this lens (Bowen, 2006; Thorne, 2008). By attempting to focus my analysis on the importance of the “story” content to the ways participants experienced the WPTA, I came to further comprehend the importance of the relational aspects in this context. This analysis crystallised the need for a specific analytic focus

on first encounters providing the foundations for the “story” content to be introduced. At that point, the interviewing and analysis zoomed in on the ways participants described first encounters, where these were available.

Beth’s story was used extensively in this part of the analysis. Beth is a woman in her 50s who suffered sexual abuse in her adolescent years and had been referred for immunological conditions to the immunology clinic. Beth’s story was revealed in the first encounter, where, from her perspective, the WPTA hospital clinician illustrated the link for her by highlighting the onset of the condition at the same time as the abuse. Beth’s was the only interview in which the participant relayed a specific and vivid story, and in her interview that story was revealed in the first encounter.

Through using the story as a sensitising concept in analysing Beth’s and others’ interviews, I fine-tuned my understanding of the role the story may play in the WPTA therapeutic relationship. I came to understand that stories could be very powerful for the person *if first, there is a negotiated understanding* between the clinician and the patient about the mind and body links, and that this negotiation’s success is dependent on the quality of therapeutic relationship, as demonstrated in the following extract:

When your heart is closed, I think you are automatically closed to everything around you. But when your heart is open, and I think that happens naturally to a response to someone [speaking about the WPTA clinician] who has an open heart themselves, or who is able to treat you as another human being on the same par as them, or just on the same journey as them, then, you respond better to whatever it is that you have to. You know there’s not the doctors and the nurses up there, and I am over here. (Jane)

In unpicking what I mean by therapeutic relationship, I refer specifically to the clinician’s ability to bring their genuine and whole self into the encounter and their willingness to listen to the story the person wants to tell. Further, the analysis suggests that the quality of the established therapeutic relationship between the person and the clinician is *integral* to the patient’s willingness to engage in the WPTA experience.

The participants appeared to assess whether it was safe for them to bring the whole of themselves, including their story, to the clinical space, and whether they were going to engage in the WPTA therapeutic relationship, including the “story” aspect. My analytical focus, in unpacking this initial assessment by participants, was on listening. Participants spent a lot of time during the interviews enunciating the value of feeling

listened to. The analysis suggests that their judgements on the clinician's ability to listen were interpreted as "cues" in helping the participants decide whether or not to engage with the clinician (WPTA or others).

The analysis revealed that participants chose whether or not to engage in the WPTA process based on the way clinicians interacted with them, rather than the content of what they were saying. In one interview where the participant found the WPTA very confronting initially, the participant described their initial experience of the clinician as *"it's not like she's listening"* which was experienced as similar to previous unsatisfactory experiences where *"I have always had the problem with the doctors, doctors that don't actually listen to you"*.

Indeed, in a study of helpful and unhelpful communication with people who suffer from cancer (Thorne et al., 2005), the authors came to understand the centrality of the human connection that the participants experience as "being known", as an experience of being acknowledged as a person in the inherently difficult context of living with cancer. This study's findings have parallels to my own findings. The sense of "being known" by patients was certainly evident in the current study. As was the case in Thorne et al. (2005) study, there was no "one way" of participants feeling as if they were "being seen" by clinicians. Some described it as, *"Well, you know, she's on song. She's seeing me as a patient"* and others as *"she is with you, she is very much with you. She's not somewhere else."* Others contrasted that feeling with other instances when they felt objectified in the system, like Valerie, who had extensive experience with the medical world. During her interview, she recounted one particularly bad experience with a specialist in a hospital setting. In contrast, when reflecting on the WPTA physiotherapist she described the sense of *"there's no judgement, there's presence, full presence... You just know. You can feel it. You know you can feel the difference"*.

In the interviews, clinicians who adapted their orientation to the person in front of them appeared to have been experienced as healing. This appeared to be the case whether clinicians operated from the WPTA or not. For example, Jason, a man in his 20s with severe urticaria, experienced his GP (who was not WPTA trained) as attending to him fully. Jason felt this was the case because the GP took the time to explain how things were connected: *"That comes back to [names doctor/GP], he was the only doctor that really listened to me. And even if I was wrong, he would always, he was able to talk me through it. And in my mind that always kind of reassured me."* Jason felt respected and

acknowledged by this doctor, and as such he was willing to engage fully with him, follow his advice and adhere to his course of treatments.

In contrast, Jason described his first encounters with the hospital WPTA as unsatisfactory when she raised with him the possibility of mind-body connections. The analysis revealed that this may have been because the clinician did not take the time to negotiate an understanding of those links with him, did not take the time to listen to the story he wanted to tell (one of physical symptoms and disruption to his life) and as a consequence he experienced her as “not listening”:

When I tried to explain [the physical nature of his symptoms] I was cut halfway through and told “No, this is what is happening and this is what you need to do.” So, when I walked out of the room I was kind of like... oh I still feel [that] what I am trying to say, I haven’t been able to get it all out. I haven’t been able to say... it was kind of like, I don’t know what’s the word? Kind of like, going to the shop and wanting to buy a Big Mac but walking out with an ice cream instead. And that’s not what I hoped to get out of it.

The first encounter negotiation may be interpreted by the person receiving the care as an attempt by the clinician to individualise their approach to the person in front of them. Patients may make this assessment by critically responding to what the clinician is listening to, and the respect they have for the patient’s own understanding of their condition. Indeed, Thorne et al. (2005) suggested that patients or persons can “discern the difference between that which is standardised and that which ‘feels’ individualised” (p. 895).

Another way to underscore the importance of these negotiations in the first encounter is by comprehending quite how viscerally scary and threatening the experience of understanding the impact *of their own specific life story on their illness* can be for a person with an already debilitating chronic illness. In the interviews, there was a sense of going into uncharted territory in understanding these links, the sense of fear of trying something so very new and outside the main discourse around chronic illness. Lorie, who had a number of life debilitating conditions, recounted early on in the interview how “*in the beginning I found it too painful to accept that anything in me could be contributing to the disease process*”. Through the analytic process, I came to comprehend the importance of acknowledging how destabilising this experience may be for the person, irrespective of their levels of “readiness”.

Valery is a woman in her 40s who had suffered for many years from severe and chronic pain and symptoms. She is a regular practitioner of yoga and practises breathing. She had had many successful encounters with complementary medicine and went to see the WPTA physiotherapist after researching the field. One could argue that Valery was “ready” and willing to engage in the WPTA. Indeed, she described in her interview how “open” she was to this way of understanding health and wellbeing.

However, even though she was open to the WPTA and described the physiotherapist as warm and encouraging, she described comprehending the possibility of exploring the specific relationships in her life and how they might be related to her condition as “quite scary”.

When you are sharing things about your childhood, and emotions that make you cry, with somebody else, it's quite scary. I didn't really think I was going to go into a physio's office and have a boo hoo. Do you know? So yeah it's scary, because you don't really know what you are going to uncover when you start a process like this.

Valerie's way of articulating the experience as “scary” was particularly notable because she described the interaction as very gentle, where the clinician took every step to work with her and alongside her:

Because, I mean, I think that's quite key with [WPTA physiotherapist] treating the whole of me, this kind of... it's the fact that you know, in our last session, the conversations that we have had about [members of the family] and I... it's huge. I mean, you don't go to a physio and talk about your relationship with your [family members] and the linkages that she is making, and we are together, it's not just her, she's not feeding it to me. A slight little light bulb is going off in my head like... “Oh my gosh, I never thought of it like that”.

This negotiation to “enter the story aspect” can be successfully achieved through the WPTA clinicians' ability to convey a multi-layered and nuanced ability to listen, and take their patients on a gentle journey, adapting to what the person in front of them requires for them to participate in the WPTA. This appeared to be the way the participants discerned whether the approach was individualised for them.

The analysis suggested that only once this negotiation was successful, could the story component be effectively brought into the relationship. However, in many cases, a

particular “story” might not have been accessible or necessary for the participants to experience and report benefits. It appeared that the highly experienced WPTA clinicians were sufficiently skilled, and therefore able to achieve a successful negotiation in the first encounter - but even then, some participants found it overwhelming. This was evident in Beth’s interview where she recalls telling the experienced clinician, *“Look, in future, you should tell people you are going straight for the jugular, not just do it!”*

The analysis of the first encounters focused on what it was that clinicians actually did, in their manner and interactions, which participants spoke of. Participants contrasted feeling “listened to” with feeling “not taken seriously and not listened to”. It was as if participants were using these observations about the listening component of the interaction to judge whether the clinician’s behaviour was congruent with their espoused intent to treat them from an integrative mind-body perspective.

Engaging with the data revealed subtle aspects of the listening practice, which together contributed to the whole “feeling listened to” experience. Figure 6 provides an overview of theme three, along with the five key related sub-themes. Each of these is discussed in more depth below with reference to supporting data.

6.6.1 The art of listening

When probed as to what it was about the clinician’s manner and behaviour, which made them feel listened to, participants spoke of physical gestures and mannerisms that invited them to speak, and assured them they were indeed being listened to. They described those as practices of good listening. For example, Claire, who has suffered from “difficult to diagnose” symptoms, recalled her first encounter with the hospital WPTA:

She’s, I feel like she really listens to me. She doesn’t just throw questions at me, like a lot of previous people I have seen did. It’s just so many questions, it’s just, I got lost. She listens to me, and she’s a very warm person, she’s very inviting. She is very warm, she’s inviting, and she just has a presence about her that makes me feel very comfortable. She’s not intimidating, she’s not sort of sitting there, legs crossed, just, you know... I mean, she does write things down, but her mannerisms and the way about her make me feel very comfortable.

With participants who saw WPTA physiotherapists, this sub-theme was experienced in the ways the clinician was able to combine their clinical expertise with the ability to make the person feel at ease and therefore able and willing to share. Their experiences

echoed the essence of this sub-theme in the interviews with participants who were seen in the hospital context, despite the two very different settings. Jane, who saw the WPTA physiotherapist for chronic pain, described:

When you go and see her, firstly she is a lot more engaging with you. She is a warmer person. She is just naturally warmer ... she doesn't have that whole clinical approach. She's like another human being...She makes you feel comfortable. You walk in there. It's not staged, it's not posed.

I named this sub-theme the “art of listening” because it attended to the art of making people feel at ease, through subtle but important behavioural signals that participants observed and noted. Participants noted and made their own judgements regarding whether clinicians were looking at their screens, too busy asking questions and not listening to the answers enough.

6.6.2 The heart of listening

In closely examining what it was clinicians did that made patients feel truly heard, the data indicated that it was the ways they interacted with the participants. This was especially important in the first encounter. Amy, in describing her encounter with the WPTA clinician in the hospital, recalled how *“it was good. I felt like I was being heard suddenly. That someone was actually listening to the whole thing”*.

These ways of interacting appeared to be reinforced in subsequent encounters where participants seemed to be assessing whether the clinician was being open to hear the story that the person wanted to get across. The story was whatever was important to the patient to tell - be it specifically about their symptoms, journeys through the health system and how their illness affected their life, or biographical stories about their psychological, emotional and relational life. There was a sense of really being listened to, which was communicated throughout. Greg, who saw a WPTA physiotherapist for breathing exercises because of his significant post-operational pain, described how *“I guess [WPTA physiotherapist] became the first person who really listened to what was wrong, didn't say ‘I can cure you’.”*

True listening was experienced as a mark of respect for the personhood of the patient. Accordingly, I called it the “heart of listening” because it appeared to speak to the essence of the experience of feeling listened to and heard, without being rushed or pushed to tell a “certain” story that “fitted” with the clinician’s worldview. Be it a dualistic, clinical worldview seeking to find a clear aetiology observable under the

microscope, or to find a biographical life “story” which may explain the symptoms, participants wanted to be heard. For example, Jason described the experience of going on to work with a WPTA psychotherapist as:

She was able to listen, hear my story, never changing it but always offering explanations on how. Not just saying, “This is why it’s happening and this is what you need to do.” But she always... talked it through until eventually in my mind I was happy with what I was hearing, I wasn’t told, “Take this, or do that, and you will be better. See you later”. (Jason)

I began to identify/construct the importance of listening to the story the person wanted to get across during the secondary analysis process as illustrated in the following memo from December 2015. *“As I listen to it [video interview with one of the women] for the second time, it is dawning on me that this sense of being ‘seen as a person’ from the patients’ perspective has something to do with the permission to talk about what they themselves see as relevant.”*

Participants spoke of a sense of relief when they finally felt that the clinicians listened to what it was they wanted to share and talk about. Of not being forced to answer a particular line of clinical questioning: *“Well, it felt really good, because it felt like what it should feel like when you go to a clinician. Like taking every point into consideration, especially from a [hospital clinician] I didn’t expect that. It’s like really, really, like you know, good” (Ben).* It is worth noting that the participants, with their extensive experience in the health system, were surprised to encounter that type of listening from a mainstream clinician. Furthermore, the benefits of the experience appeared to have been amplified because the clinicians had a credible “mainstream” professional identity.

Whether it was a WPTA clinician in the hospital setting, or a WPTA physiotherapist in private practice, this sub-theme was consistently present throughout. The data suggested that participants made informed decisions regarding how much they were willing to share with clinicians. They did not automatically share everything with a professional simply because they had the training. Participants had to feel secure in the relationship with the clinician before they chose to fully participate in the therapeutic relationship. I chose to include the following longer extract from the interview with Pauline, the young woman who suffered from chronic pain of which there was no clear aetiology, because her reflections appeared to capture the essence of this sub-theme.

I think a huge point of difference between my GP and [WPTA physiotherapist] is that I trusted [WPTA physiotherapist] and I trusted her to not ridicule me. I trusted her to be honest, and be straight with me, and not dismiss me. And I think it's really important to have that level of trust in a health professional, because it's been something that I wanted to have. But I do think, it's not something you automatically are going to have in a health profession. I think a lot of doctors kind of think you are going to trust them, and you are going to feel like you can be honest with them, and tell them everything. But when, particularly when it is really sensitive information, or you know like, really deep insecurities, ...it's not something that I am going to readily confess to (laughs) someone, without any kind of level of being able to gauge how they are going to respond. So I think that it's really important for the whole person approach to work, that you have to show the patient that you are going to be patient, and you have to show them that you are going to listen, and that you are not going to override them.

This extract illustrated further how the clinical encounter is a co-constructed process between two active agents. In the present research, participants were constantly making assessments and judgements regarding the “credibility” of the health professional in respect to their willingness to trust them. They were observing and making internal decisions as to how much they were willing to engage. This formed part of whether or not they were “ready” to engage. Further “flipping” the discussion from whether the patient is “ready” to engage in the therapeutic relationship, is to consider what it is about the clinician’s own conduct and practice which facilitates this.

6.6.3 The act of listening

In drilling down to understand how listening was experienced by participants, it became evident that it was important to participants that the clinician was not just “listening passively”, but engaged with them in meaningful and helpful ways. In calling this sub-theme the act of listening, I chose to highlight the active listening component of the experience, which was often described as the clinician “making the connections”. Participants experienced the listening as more than “just” being given the space to speak, but as an active and engaged process where the WPTA clinician was making connections for them to reflect on and then do something with them.

Each clinician had their own style of practising the act of listening. Some would tell stories:

She would listen to me, then she would say, “When you are talking to me the picture I am getting inside is a picture like this.” She would tell me a picture story, or another story that linked in with what I am saying, which often had a hard moment for me like I would go “Oh”, and I would suddenly get it. (Lorie)

Others would ask wide and varied questions touching on different aspects of the person’s life:

And then I come here and I sat down. And then she asks me questions like, “Ok, so what was your birth like? What are the members of your family and what are they like? And what is their health like? Have you had like, how’s your mind state? Have you had any stress?” If I did say something like an event was happening, she would say, “Ok, how does that make you feel?” Stuff like that. And like, I think it’s, you know, it makes me feel like I am addressing aspects of my illness a lot more. And I am getting like, you know, I am in better care and I am making more progress. (Ben)

This ability to question actively in a manner of open and non-threatening curiosity was prevalent throughout the data set, including during the secondary analysis. I chose to highlight this separately as it can be conceptualised as an aspect of listening, which goes beyond what would traditionally be termed “good listening” practice. It further highlights the human-to-human engagement which participants valued.

Moreover, those participants who had had experience with mental health professionals, highlighted the engaging nature of the listening as being more inviting, compared to more passive forms of listening they may have encountered. This is illustrated in the following quote from Dan, who reflected on previous experiences with mental health professionals where “*it feels like kind of, it does feel a little bit like talking to a wall sometimes*”. Indeed, the descriptions of active listening in the data were closely followed by reflections on the grounded, yet flexible professional boundaries described earlier. It could be suggested that the act of reflection, and asking questions in an active manner, may have been interpreted by participants as clinicians having “clear, yet flexible boundaries” because of this willingness to explore and work with the patient in a partnership.

6.6.4 The craft of listening

This sub-theme was unique to the experiences of people who were seen by the WPTA physiotherapists. I chose to include it as a unique sub-theme even though it was not

present in the other interviews, because it powerfully illustrates that explicitly acknowledging and “bringing” the body into the encounter can enhance the sense of feeling “heard”.

Participants who saw such physiotherapists appear to have felt very assured and comfortable in experiencing the combination of touch and talk. As outlined previously, this could be because these clinicians were very grounded, yet flexible in their professional identities and professional boundaries. The following extract may be helpful in illuminating how the touch can reinforce the experience of being listened to:

It was almost like, well the way she massages you is very relaxing. So it's subtle, but there's deep work. So I am in a relaxed space. There is something nurturing about it as well, and she is very warm, her hands are very warm. So there is a combination of all of those things. You are relaxed, you are lying down, you know. I felt really able to just talk. Which is kind of odd because she is right in my space but there was something less confronting that I wasn't looking in her eyes, but I knew she was there, that made it even more comfortable to talk.
(Valery)

Because of the physicality of the encounter, I termed this sub-theme “the craft” of listening to highlight how beneficial participants found the experience.

6.6.5 Observing and acknowledging

Another aspect of the first encounter worthy of note was the practice I termed “observing and acknowledging”. The WPTA clinicians, often in the first encounter, observed and acknowledged something unique about the person, something like an aspect of their biography which might be related to their physical symptoms, without “forcing” the person to address, confront or resolve what was observed.

Participants experienced this as an absence of any judgement. They specifically commented on how they did not feel “judged” for not being able to “cure themselves”. This was especially present in (but not limited to) the interviews with people who suffered from conditions which were hard to diagnose. There was an almost palpable sense of relief by interviewees about this shift in the clinical focus. The following example from a person who saw a WPTA physiotherapist may illustrate this point further:

She said to me at the end, which was quite key of last appointment was, because I was just like “Oh, now what do I do?” Feeling a little bit lost with this whole thing [a realisation about a possible connection between her biography and her symptoms] and, oh that’s what I said to her, “How can I make, essentially make this [the chronic condition], make it get out of my body, release?” That’s the word I used “How can I release this?” And she said, “Well, in my years of experience and seeing this before, it’s not necessarily a releasing. It’s an acknowledging. And then we go from there.” (Valery

In summary, theme three captured a clinically important aspect of the analysis, by providing insight to the practice of listening in the WPTA context. It elucidated the value participants placed on the experience of feeling listened to and truly heard, as a form of pre-requisite before they “allowed” WPTA clinicians to gain access to their “whole”. It further described, in some depth, the practices clinicians used to achieve this.

Theme three specifically illustrated the co-constructed nature of the therapeutic relationship. Participants appeared to make judgements about the clinicians in front of them in an active and quite mindful manner. These judgements appeared to be quite formed following the first encounter. This crystallised the importance of clinicians successfully negotiating these first encounters in order for participants to go on the WPTA journey alongside them.

6.7 Theme four: A door into understanding

Figure 7 provides an overview of theme four, along with the three key related sub-themes. Each of these is discussed in more depth below with reference to supporting data.

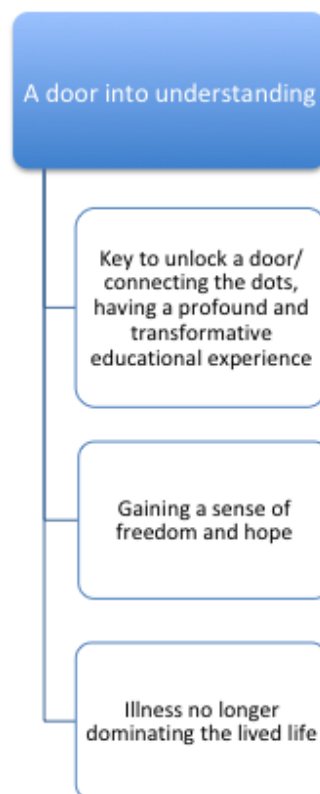


Figure 7. The relationship between theme four and the three sub-themes from which it was constructed.

The name for this theme came from one of the very first interviews analysed during the secondary analysis phase. Christine, one of the women interviewed in the video project, recounted her experience and reflected on what it was like, and what was most impactful about it. When answering the interviewer she said, *“I think the thing that mattered to me, was that it was like a door into understanding.”*

This theme appeared to be central and unique to the WPTA experience. Every participant found the most beneficial aspect of the WPTA experience to be the insight they gained into the impact of the mind-body connections on their symptoms/condition, in the context of their own lives. Throughout the analysis, this notion of opening “the door into understanding” was articulated as unique to the WPTA experience. That is, participants’ understanding of these links as a consequence of the WPTA was how they differentiated it from other positive therapeutic relationships they had during the course of their illness. They also identified this aspect of the experience as unique to the approach.

It appears that experiencing the WPTA resulted in participants developing new understandings about the connections between mind and body, and how they specifically manifested for them. Different clinicians facilitated this insight for their

patients utilising different techniques. Successful negotiation of the first encounter laid the groundwork for this facilitation to be successful. Indeed, all the participants appeared to have had a transformative educational experience through the WPTA, which enabled them to “*connect the dots*” and “*open doors into understanding*”. For this study’s participants, this experience was profound and freeing. In-depth illustrations and exploration of this experience are provided below.

Understanding the connection between their lives, emotional states, and physical conditions was experienced as a door being unlocked, and dots connected which resulted in a profound and transformative educational experience for participants. Understanding the connections, in the context of their everyday lives, offered participants a way out of living a life dominated by their ever-present and unpredictable body. Through this understanding, they were able to create strategies to deal with and recognise personal situations which may lead to the onset of symptoms or deterioration of their health in the context of their lived life. This resulted in them gaining a sense of freedom and hope. As a consequence of this experience, even if they still had some symptoms, their illness no longer dominated their lived life.

6.7.1 Key to unlock a door/connecting the dots, having a profound and transformative educational experience

Every participant in the primary study described how, through their interaction with the WPTA clinicians, they gained an understanding of how their emotional states and life experiences may be linked to their health status. This was also the case in all of the interviews analysed during the secondary analysis phase. From the outset, the metaphors they used were powerful in-and-of-themselves, e.g., “a key to unlock a door” and “connecting the dots”. However, through the analytic process, I came to appreciate that their specific choice of metaphors may in itself be central to understanding the essence of how they experienced the approach. The active choices participants made in describing the experience as a catalyst which helped them open a door, or connect the dots, can be interpreted as WPTA providing access to an understanding that may have been there, but that they had not before been able to access. Therefore, the experience of WPTA may have empowered them to draw on their own resources and as a consequence feel more in control and therefore more able to manage their own health status.

This was especially evident with participants who had had their own inklings or understanding of how their mental and psychological states interacted with their health,

because they had privately observed it. However, they perceived that making these observations was unwelcome in the clinical encounter because of the traditional focus in biomedical settings on identifying a visible aetiology for symptoms. Understood this way, “opening a door” becomes opening a door into an understanding that was *already there*, and making it accessible or activated. Furthermore, it may be the case that this validation of the patient’s own theories about these connections, may be experienced as empowering and validating of their own agency and ability to overcome their illness/symptoms. For example, Ben recalls:

I did also have like an inkling that maybe my psychological like state can have a very strong impact, on like, the state of my skin. Because I know when I am happy, my skin is very, very clear, and then as soon as something, like adverse, goes wrong, then my [diagnosed condition] sort of dips down a bit, and I get a flare-up. And like throughout my life, [but] I thought it was just as another doctor told me, [that] it has to be like a certain cause, it’s just like the foods I am eating or skin products I am using.

In a memo I wrote subsequent to listening to one of the video interviews during the secondary analysis phase, I noted:

This woman had a lot of her own resources in how she sees life, her own theories and seeing of connections – in this subsequent engagement with the video, I can see that in the therapeutic process, the clinician respects these resources and brings them to the therapeutic experience in an authentic way. Reflecting on all eight interviews that I have done the secondary analysis on, I can really see that this is a sub-text of the patients’ theories, being “allowed”, “respected” for the resources that they bring. (Memo, 29/2/2015)

Throughout the analysis, I consistently noted what seemed to be the legitimising/empowering experience of the WPTA in validating patients’ own pre-existing inklings about the connections between their symptoms and life experiences. Participants who did not have any inklings, or theories, also found the process of making these connections very helpful in understanding how their histories and psychosocial experiences interacted with their health. As a consequence, they developed a nuanced awareness of their illness in the context of their life. Beth, whose story directly related to her illness, described how she now understood the illness in the context of her life:

And so we spent a lot of time talking about how, the fact that when life got hard, because I couldn't in my mind do anything to work it out and help it [the abuse], I had an attack which avoided the whole issue and took all the attention off what was happening.

6.7.2 Gaining a sense of freedom and hope

Through building the understanding of how their minds and their bodies may be linked and may influence their illness and symptoms, the WPTA appeared to have helped participants gain a sense of being more in control over their symptoms/condition. This seemed to be the case even if participants did not have a diagnosis or were not yet free of symptoms. In turn, it can be suggested that the process enabled participants to move beyond their condition/illness and appeared to influence their sense of feeling hopeful about their health.

Initially, during the NVivo phase, I used the code of “control” to classify quotes that related to this sense of gaining control over symptoms, which I saw as central to the experience. It was through an exchange with one of the participants, during the primary data collection phase, where deeper reflection occurred. This participant helped me comprehend that central to this profound educational experience was the sense of freedom and hope this engendered, rather than the more tactical aspect of controlling the symptoms. This experience shifted the analysis to articulate how deciphering the connections may have led to a subjective *sense* of feeling more in control which, in turn, appeared to contribute to the more essential experience of freedom and hope. This existential experience was present even when symptoms were still present. The following exchange with Lorie facilitated my thinking. I chose to include it in its entirety as it further illustrates the co-constructed nature of this research:

Me: How do you now view your condition? Before it was something “that was wrong with you”, you said, “in the body”, and now how do you come to view it?

Lorie: Earlier I said, when I eventually gently accepted the fact that my mind and my body are connected, that they talk to each other in their mind-body talk. With messages, hormonal messages or interactions or whatever it is, nerve impulses. When I gently accepted that, that actually happened, and that it could contribute to disease, I became hopeful. I became hopeful that the conditions could then change if I unlocked the negativity, or if I unlocked the secret of that conversation, I think that's really it.

6.7.3 Illness no longer dominating the lived life

Through the WPTA experience, participants came to new understandings about their health. They had an educational experience, which seemed to change the ways they now perceived their condition. Participants appeared as if they no longer experienced their conditions as unpredictable and “scary”. They reported being less preoccupied with their health status as they spoke of no longer being dominated by their illness in their day-to-day lives. They felt able to take more risks and were no longer dominated by their illness or symptoms.

Ian, a man in his 60s who had had years of severe symptoms which finally got diagnosed, and who experienced the WPTA in hospital as well as with a private psychotherapist, reflected that had he been introduced to the WPTA earlier, the first years of his illness would not have dominated him to the extent that it did.

I think in the first 5 years or 6 years my entire focus was on the body side. And you don't really cope with that because it's happening. Well, you cope physically with your day-to-day life. But you don't, it dominates your life, put it that way. And it dominates what you do and what you think and what you read and everything. And what you talk about. And so the mind-body side would have been, the mind side would have made me able to have the body side, but not to have it dominate me.

Absence of symptoms, according to the participants, was not the key for feeling this sense of freedom. Indeed, in the context of WPTA physiotherapists, the therapeutic focus according to participants seemed to be more concerned with finding ways to manage the symptoms rather than a pressure to become symptom-free. What appeared to be a mindful lack of pressure on patients to be “cured” was outlined earlier in the section on the sub-theme *observing and acknowledging*. Participants did not feel burdened by the clinicians’ expectation that they will become free of their illness or their symptoms, as they did with other clinicians. That experience in itself was perceived as “freeing”.

Through gaining the understanding about the connections, participants felt more able to live a full life. This is illustrated in the following extract from the interview with Pauline, a young woman suffering from unexplained and extremely painful attacks who was seen by a WPTA physiotherapist.

The main thing that I think that I gained is that beforehand I just felt so powerless and I had no way of coping besides pain medication. And I just felt, you know, I was definitely starting to doubt myself as well, like, you know. Because there had been months and there was no diagnosis, I just felt, “Oh, my god, what if it is all me? What if you know I am wasting everyone’s time and there is no cause?” I just felt so, you know, like powerless, and so afraid that I was second-guessing everything. And when she [the WPTA physiotherapist] said, “Look, here are these ways of coping with it which are practically really, really useful” and I use them all the time. (Pauline)

In summary, theme four attempted to capture the essence of the content of the WPTA experience from the perspective of the people being treated for their chronic illness. Participants appeared to have had a profound educational experience through gaining an understanding of the connection between their lives, emotional states, and physical conditions. The terms they used such as “connecting the dots” and a “door into understanding” suggested that, for some, the WPTA allowed them to draw on their own existing observations of these links, and “gave them permission” to draw on their own resources in managing their illness/conditions.

Understanding the links between mind and body in their own life’s context appeared to have offered participants a way out of living a life dominated by their ever-present and unpredictable body. They extensively communicated how, through this understanding, they were able to proactively create strategies which helped them in feeling more in control of their condition, and contributed to their sense of agency. This, in turn, resulted in them gaining a sense of freedom and hope. As a consequence of the WPTA and comprehending these links, participants felt as if their illness no longer dominated their lived life, and that they were able to live a full life, even if they still had some symptoms.

6.8 Overall summary

The findings chapter was organised to reflect the research question:

What can be learned from an in-depth consideration of the experience of persons treated in the non-dualistic WPTA for their chronic conditions that could be of general relevance to improving the mainstream care approach of chronic conditions?

In answering the question, four distilled and crystallised themes were constructed from 14 sub-themes. Theme one, **seeing patients as persons and explicitly acknowledging their unique history**, captured the importance, from the perspective of participants, of acknowledging them as people first. It is as people that they have endured chronic symptoms that have altered the way they live their lives, and at times, altered their sense of who they are. It highlighted that people with chronic illness arrive at the consulting room of any clinician with extensive experience in the “system”. Participants frequently appeared to use these experience as a reference point from which they chose whether or not to engage in the therapeutic encounter. Therefore, it brought to the forefront the importance of clinicians’ ability/willingness to create the space for the patient to bring all of that into the therapeutic encounter.

Theme two, **clinicians bringing their whole selves into the therapeutic encounter**, captured the place and importance of professional identities, clinical expertise and boundaries within the WPTA experience. It spoke to the delicate balance between the importance placed on clinicians’ clinical expertise and their ability to bring themselves as whole persons into the clinical encounter from the perspective of the person being treated. It highlighted how clinicians who were able to see the person in front of them as an expert in their own illness, create a sense of working alongside the patient to achieve a positive health outcome for them. This experience appeared to result in participants describing care experiences that were centred on them.

Theme three, **negotiating first encounters**, provided insight into the patients’ perception of the practice of listening in the WPTA context. Theme three focused on participants’ need to feel listened to and truly heard, before they “allowed” WPTA clinicians to gain access to their “whole”. Participants appeared to quickly form these judgements, often following the first encounter. This theme crystallised the importance of successfully negotiating the first encounter in order for patients to engage in the WPTA process, and highlighted the ways in which clinicians achieved this.

Finally, theme four, **a door into understanding**, attempted to capture, from the perspective of the people being treated, the essence of the WPTA. Participants reported to have taken part in a profound educational experience. This was because, through the WPTA, they had gained an understanding of the connection between their biographies, emotional states, and physical conditions. Understanding these links appeared to offer participants a way out of living a life dominated by their symptoms and conditions. Through these understandings, participants were able to proactively create strategies,

which helped them in feeling more in control of their condition, and contributed to their sense of agency. This, in turn, appeared to have resulted in them gaining a sense of freedom and hope. As a consequence of the WPTA and comprehending these links, participants felt as if their illness no longer dominated them.

Chapter 7: Emily’s Story

7.1 Introduction

As outlined in Chapter 5, Section 5.5, once the analysis was completed, I searched for a way to communicate the essence of the analysis as a whole (Becker, 1986). In that section, I detailed the methodological steps undertaken in constructing a composite vignette of the findings, guided by the writing of Ely et al. (1997) and Spalding and Phillips (2007). In this chapter, I share this vignette. The story is presented as a research interview where “Emily” reflects on her encounters with the medical system and her WPTA clinician in the course of her experiencing severe symptoms of allergy and eczema, two common conditions seen by the immunology department.

As outlined in Chapter 5, I opted for this format as a way of acknowledging the co-constructed nature of the interview process in qualitative studies. As such, Emily’s story is a pastiche that weaves together quotes from the primary interviews including from people seen in the immunology department as well as by WPTA physiotherapists. I have also included direct quotes of my own questions during the interviews in my primary research. All the quotes in Emily’s story were taken verbatim from the primary data. The connecting narrative, however, has been fictionalised so as to not compromise the anonymity of interviewees.

7.2 The pastiche vignette

Emily is a woman in her early 30s who has suffered from eczema and allergies since her early teens. These conditions are why she is being seen at the immunology department at her local hospital.

In the first few minutes of meeting her, my impression is that she is well spoken and takes care of her appearance. She looks at ease and her skin appears healthy. We share some small talk; she tells me about her work as a teacher in one of the city’s well-known schools and how much she loves it. She looks Pākehā (New Zealand European), but, at the end of the interview, when I ask her how she describes herself culturally and ethnically, she tells me that her grandmother was Māori and that her Māori heritage is important to her.

When I explain the purpose of my research, she appears palpably excited to participate and share her experiences.

I take out a piece of A3 paper, and explain to her, *“I’ve got this A3 size paper, what I find really helpful is if you can talk me through your illness, when you first had symptoms so that I get an orientation of your experiences in the health system. The purpose of the research is really about your experiences and specifically about your experiences here with [WPTA hospital clinician]. But to understand your experiences here in the department, I need to understand what happened before as well.”*

Emily replies enthusiastically, *“So I suppose I should start right from the beginning?”*

I reply, *“Yes, wherever you want.”*

Her mood turns reflective. *“Ok, so I think it started when I was around 10, maybe 11. And I started to get like rashes all over my body. I think my mum took me to the doctor and they just told me it was a rash and to ignore it. And then I got taken to another doctor who was a GP but had allergy training and he told my mum that it was allergies. And eczema as well, I was told that it was eczema. I was just head-to-toe covered in eczema, from my face down to my feet. So I got allergy testing done and I came up positive for quite a few allergies like anaphylactic to dairy, and shellfish. Those are the main ones. And pretty much from there that’s where it started.”*

I ask her about the ways in which the eczema and allergies impacted on her life. She bursts out with a short laugh and tells me that when she was a teenager there weren’t many ways in which they didn’t impact on her life.

“Like having to be on prednisone for like long periods of time, long periods of antibiotics. My skin was so bad that I couldn’t walk properly sometimes because I had really bad eczema behind my knees so I had to walk with like stiff legs, it was horrible. So I couldn’t really do a lot of exercise. I put on a lot of weight. I was severely impacted. And like having severe allergies is a big impact on your social life as it is because you know like birthday parties when you were young, you can’t eat the food, you’d always have to bring your own food. School trips, shared lunches at school.”

Emily thinks she had really low self-esteem and possibly even depression. Because the eczema was so visible, and she thought she’d be made fun of, she rarely socialised with teens she didn’t know well. She talked about “her body” doing things that she had no control over, things that were really quite scary because she never knew when a flare-up would happen.

When she was 17 or 18 and doing exams at school, her eczema was so severe it resulted in a serious infection. She had to be hospitalised right in the middle of her exams. This meant that her results were not as good as she could have achieved, but there wasn't much she or her parents could do about it. She also tells me how she really struggled with the side effects of the medications she was prescribed as a teenager. They made her feel very tired and often very nauseous. She lost weight and lacked energy all the time and therefore stopped playing netball, which she'd loved.

I listen and nod and acknowledge that she has had a lot of experience with the health system.

Emily replied, *"Oh yeah, a lot. Just going to different appointments all the time. Because we [Emily and her parents] would go to different specialists for allergies and we wouldn't quite like them, and then we would change and go to different ones, then go to the public system, then try different private ones again. We'd go for eczema, then go for my allergies. So I sort of had a lot of experience with different doctors over the years."*

I check what made them change doctors and switch between the public and private systems. She thinks for a moment and then explains that both she and her mum had some ideas about other, less invasive, ways to manage the eczema.

She tells me about one of the specialists they saw *"just was shutting us down with every single suggestion we made, because it was outside of the scope. He didn't understand what we were talking about by these other strategies, we felt like we were going over the top of his head because he just wanted to focus on what he has always done for eczema and he didn't care it wasn't working for me. He was bordering on rude and arrogant. And almost couldn't even make eye contact with my mum or me. I was present to him but not properly and I found that, but even the whole, he was essentially telling me that my only option was to keep taking these medications that had unacceptable side effects for me."*

When they walked out, they decided not to follow his advice but instead to seek someone who would be more considerate and who might "listen more".

At this point, she tells me how she ended up finding a more holistic doctor before she turned 18. I ask her to clarify what she means by "holistic".

Emily explains in some detail. *“Well, she was a dietician, a registered dietician. And then she also was a, I think she was an immunologist, too. But she also had like a biomedical background and she specialised in holistic treatment of allergies and eczema. She looked at every different aspect of my life like to help each treatment. She believed that my eczema and my allergies were all tied together and that I could sort of help them by getting my diet better. Trying different approaches to medication. Trying different treatments, not just medications. There was some of that too but things like doing sinus rinses, different types of treatments for eczema, so like baths and all that sort of thing. And it really helped me a lot.”*

Emily needs very little probing and I say very little, mainly nodding, smiling and listening as I take notes. The experiences seem to flow from her as she tells me both about the bad encounters with medical professionals and also the good ones, where she felt the clinicians acknowledged how much the symptoms had damaged the way she lived her life.

“You know,” she says, “those doctors who just saw me as a young woman who is having these terrible experiences with eczema that is just not getting under control, they were so great, made me feel like they really ‘got it’, got how hard it was for me.” She then tells me about a specific specialist who asked her, *“‘Do you mind if I just give you a hug?’ And I was just like, ‘Oh, thank you, is that because this is really horrible?’ You know? I felt like he might have a daughter and she might go through something like this.”*

Emily tells me how after those tough couple of years and seeing the holistic doctors and the kind specialist, she finally found a regime combining conventional and more natural remedies that gave good results for a number of years. She ended up with a highly restricted diet that seemed to work at the time. She describes the effort of keeping up with the restricted diet as nearly a full-time job, and laughs. Fortunately, her parents were very supportive and were in a position to afford the diet, which was quite expensive to maintain.

The symptoms continued into her 20s, causing her issues at times, but kept largely under control with the diet and the medications. Emily was able to go about her life and have far more freedom. Like so many Kiwis, she travelled abroad and returned to New Zealand in her late 20s.

Emily tells me that on her return the symptoms at first remained largely under control. She was living with a boyfriend at the time. Then, as she started work as a primary school teacher in a tough neighbourhood in town, the symptoms flared up again. They became worse and worse to the point there were days she couldn't go to work. Emily tells me how the eczema would get so bad that she could barely walk. Worse still for her as a teacher, she laughs, she couldn't turn up covered with a visible rash!

The diet, she says, seemed to become less and less effective, and no matter how restricted she kept it, the symptoms continued and the medications weren't really helping either. The symptoms restricted her ability to work and also put pressure on her relationships. She finally decided to go to her general practitioner. That kicked off another round of specialists' visits, including spending hours on end at different medical practices, and the enduring further changes to her medication. She also bore further restrictions on her diet, to limited avail.

It was at this point she was referred to the immunology department in her local hospital where she first saw the WPTA clinician. She recalls how her GP decided that her best route would be to see the hospital team to try and wrestle her condition back under control.

I ask her to go back to that first time she met the WPTA clinician and reflect on what it was like.

Emily reaches for her bottle of water, hesitates a little and replies, *"Well, it wasn't at all what I was expecting and felt like a bit of a shock really. It was a huge shift."* She laughs. *"I think I was expecting another medical sort of talk. Well, I assumed in my ignorance that she would be a bit more like all other doctors I had seen...you know...check the nose, check the chest, do all the normal questions and all those sorts of things."* But, she tells me, it was very different. She recalls how the WPTA clinician asked her all kinds of questions about her life, which felt a bit strange in the clinical hospital setting.

I ask Emily what made her engage with the clinician asking these unusual questions even though it wasn't what she had expected after being referred to the immunology department at the hospital. She explains two key things, first that she was so desperate to "get on top of this thing" that she would have given just about anything a go, and since it was in the hospital she had faith that the clinician "knew what she was doing".

Secondly, she tells me that there was something about the clinician. Emily felt like she could tell her things she hadn't told other people, she felt it was "safe" and that it would be OK to talk.

"She was very relaxed, made me feel relaxed. And was just generally really good, you know. It wasn't like going into some specialist and you sit there and you get agitated and anxious all the way through, you know, you sat there and thought, 'I wonder what happens here?'"

Emily talks about how, in that first encounter with the WPTA clinician in the little consulting room in the hospital, she truly felt listened to by a doctor and how that sense of being listened to was so important to her. In fact, she says this was the first time since she had turned 20 that she felt listened to by a "mainstream" clinician.

That fascinates me, and I ask, *"What is it about her listening that you know she's attentive?"*

Emily turns her head from me as she is thinking hard. She replies, *"I felt like she really listened to me, she didn't just throw questions at me like a lot of previous people I have seen did. It's just so many questions, it's just I got lost. She listened to me and she's a very warm person, she's very inviting. She is very warm, she's inviting and she just had a presence about her that made me feel very comfortable. She's not intimidating, she's not sort of sitting there legs crossed just you know, I mean she does write things down but her mannerisms and the way about her made me feel very comfortable as opposed to some other people who I have seen who seem very, you know, like I'm just another product."*

I continue to explore these experiences, trying to understand what it was that the clinician listened to that Emily felt was important to her. She closes her eyes, sighs, and frowns as she concentrates and continues, *"Well, she was able to listen, hear my story. And then, not changing it, but offering explanations on how, not just saying 'This is why it's happening and this is what you need to do.' But she talked it through until eventually in my mind I was happy with what I was hearing, I wasn't told, 'Take this or do that and you will be better, see you later.'"*

Emily looks at me and smiles. She asks me if I know how some people are supposed to listen to you, therapists and the like, but you kind of know that they're not really. She

says that this was never the case with the WPTA clinician. She uses words like *“an active sort of listening”*.

I explore it with her and ask, *“Do you want to explain what that active sort of listening is, from your perspective?”*

Emily closes her eyes, frowns a little, then looks straight at me. She replies, *“It sounds like she has heard what I have said. Interpreted in a way that even I don’t understand. Then asked a question that helped me see the point. Or she has actually given me a little bit of instruction. Just plain straight up given me a little instruction. Or she’s told me a story that’s brought light into my world, what I was talking about. The situation or the feeling. So she has listened to me. So you can listen to someone and the person can feel heard but not helped maybe.”* She concludes by telling me how this ability to make her feel so at ease, listen so deeply, and be so engaged in what it was that Emily wanted to talk about made her feel helped.

I check with Emily whether it mattered that the clinician had clinical training.

She nods enthusiastically. *“There’s like a credibility I think which makes you walk through the door and then when you’re being treated, I think it provides you with a comfort, yeah, I think that’s the way I would describe it, a comfort of, that she knows what she is doing. And it’s not necessary that she’s a trained physician, it’s that she’s got the skills on board to help you and the experience.”*

It made all the difference to her that the clinician was professionally trained. There is no way, Emily tells me, that she would have engaged so deeply with someone who was “quasi” trained without a professional body to back them up. She didn’t mind that the encounter felt very different to those with other professionally trained physicians she’d seen in the past though, it was the knowledge that she had that background to draw on.

She thinks a little and goes on to try and explain to me that the WPTA physician was like a “cross between a naturopath and a doctor”.

When I ask her what she means by that, she answers, *“So your average doctor is often ‘Let’s prescribe you this to fix that problem.’ They are not preventative and cause-related, they are just fixers. Naturopaths are very preventive and ‘I think you might, let’s try this thing’, it’s all a little bit airy fairy for me.”* She clarifies that she thinks

naturopaths are too airy fairy. *“So [WPTA clinician’s] approach was very much in between those of scientific approach but also bringing a human approach in a more sort of natural, holistic sort of way. So getting down to the causes of things and figuring out why does your body react to things like this and digging into the actual root causes. Does that make sense?”*

I nod and say that it does. We pause. She then goes on to say how very refreshing it was that the WPTA clinician seemed to see herself as another human being, engaging with another human being on an eye-to-eye level, both of them bringing forward their expertise. Sure, Emily says, the clinician had her clinical training and years of experience, but Emily was an expert in how her illness affected her. And the clinician respected her.

Emily reflects how speaking to the clinician felt. *“It was almost like we were peers in a way. Which is very important to me because oftentimes I find that doctors think that because they are doctors they are so much better than other people and you know all that sense that ‘We have all this knowledge’. Well, yes, I have all this knowledge too, just not medical related. So that was nice, it was more like peers talking, even though she is older than me. But you know there was a sense that we would share ideas. And it wasn’t just me having to be receptive to this wisdom coming from above.”*

After a slight pause, she looks up, meeting my gaze, and continues, *“You know, there is a certain amount of humanity needed to go for the sort of holistic approach. Because you can give advice but you also need to be able to step back and let the patient be in charge and to kind of control their own sort of attempts to fix things.”*

We pause, as I take it all in. Now I feel like I can actually ask her about the content of the experience itself, what it is that the clinician does and talks about, and the ways in which she thinks it helped her. I am deeply curious about what it is that she believes has helped her in her encounters with the WPTA clinician.

She looks down as if considering my question, then up and meets my gaze and replies, *“OK, I think the WPTA clinician was the catalyst, if you like, or she was the igniter. The switch turner or the door opener. I think she, yeah, she made something available to me which turned out to be quite important.”*

I am startled by that and ask her to elaborate.

Emily is on a roll now. *“She just clearly defined the link between sort of the psychological processes and the physical reactions. And she made it quite clear to me that the eczema isn’t always going to be one thing, it is a combination of things.”*

Understanding the links between the immune system and emotional experiences was what she found helpful. That there could be aspects to her life, like stresses at work, and difficult personal relationships with her live-in boyfriend, that could be related to eczema flare-up. She says, *“The fact that she linked what happens in my mind, so mentally. The fact she linked mental with physical. And I mean you hear about these connections in books and movies, but when it’s happening to you I don’t know why I didn’t think of it. But when she finally said it, it was like, ‘Oh yeah, it doesn’t just happen to other people, it’s me as well.’ Like, everything is linked.”*

We continue to talk about the experiences with the WPTA clinician and I probe around the ways she now sees her illness. I ask her about how she now thinks about those connections. She tells me how initially she did find it “scary” that everything is connected and that things that happen to her on an emotional level can have an impact on her physical symptoms. She goes on to explain to me that after a few sessions when she really understood those connections between her mind and her body and how they might be affecting her in her own personal unique circumstances, she came to see these connections as liberating.

“When I started to assimilate the information that mind-body are connected, then I actually had hope... Because if I then address the mind then maybe the body would heal.” She goes on to elaborate even more, working hard at articulating to me what it is that she “got out of the experience”.

“When I accepted the fact that my mind and my body are connected, that they talk to each other in their mind-body talk. With messages, hormonal messages or interactions or whatever it is, nerve impulses. When I gently accepted that, that actually happened and that it could contribute to disease, I became hopeful. I became hopeful that the conditions could then change if I unlocked the negativity or if I unlocked the secret of that conversation, I think that’s really it.”

This sense that she can change things about her life, which will mean she can have less allergies and eczema, that was most liberating for her. She tells me how she was able to observe that, for example, after a very stressful day at work, the symptoms would get

worse, but instead of panicking and trying to cut more foods out of her diet, she now has other strategies in place to calm herself down, which seem to impact on her eczema and stops the flare-up from escalating.

She goes on to describe how hopeful she has become, how much more in control she feels. That the more she is in tune with her own body and emotions and what is happening in her life, the better she feels. She tells me how she can now even pre-empt attacks. *“I am very grateful that I have learned to be alert to my body and to the message in the eczema and allergies. When I feel I have had symptoms, as I have had a little bit this week, I have to remind myself, well, I choose to remind myself of what it is that is specifically happening, and how I am reacting to it.”*

For example, she tells me that through exploring the connections in the context of her own life story and her relationship with people around her, she has learnt new things. *“It doesn’t matter whether it is my mother, my boyfriend or my difficult boss. In some ways now anyone who causes great aggravation or who,” she sighs, “I can see is bringing me into a tense place where I think, ‘This is dangerous for my health, this is the scenario I could get an, a really big flare after. I can see that there’s, that this is dangerous, that the stress is getting too high, that my body is going to react.’ And so I just remove myself from it or something like that.”*

When I finally ask her how she is, she tells me that she still suffers from the occasional allergies, especially in the pollen-heavy seasons, which are a nuisance, but she manages. She is still on oral medication for the occasional allergic attacks and that seems to do the trick most of the time. The key for her is that she doesn’t get so scared every time there is a flare-up.

Emily no longer feels so helpless; like her body does these things that she has no control over. She has also completely stopped worrying about her diet, which used to dominate her life. She eats most things within reason, she socialises with her friends, doesn’t feel so isolated anymore, and feels like she can deal with stressful situations at home and at work without fearing waking up in the morning covered in an ugly rash. She doesn’t think she is “cured”, but she feels free and in control of her own body. Finally, the hours on end spent in specialists’ appointments and at the hospital have disappeared, and that’s good enough for her.

Chapter 8: Discussion and Conclusion

The primary objective of this doctoral research was to consider in-depth the experiences of persons treated in the WPTA for their chronic conditions, and to identify what could be learned from these experiences that may be of general relevance for improving the mainstream care approaches to chronic conditions. It was acknowledged at the outset that this doctoral study stems from a highly personal experience of having been treated by this approach for an autoimmune illness (Churg-Strauss Vasculitis).

Within this chapter, I discuss the novel contributions this doctoral study offers, demonstrating how these challenge and/or advance current knowledge of WPTA and the treatment of people with chronic conditions more generally. I will reflect on some key methodological considerations, discuss implications for clinical practice and further research, and consider the strengths and limitations of this research. Following summary and conclusions, I offer a postscript documenting my personal understandings following the doctoral journey.

8.1 Summary of key findings

The experience of “*being seen rather than being looked at*” captures the essence of participants’ voices, and appears to be a critical component of care. At its core, it is experienced as being acknowledged for one’s personhood within a therapeutic encounter. The findings from this research have augmented understandings of the experience of being treated by the WPTA, with novel insights about the subtle and profound aspects of clinicians’ relational practices, which shape these experiences of “being seen”. This study has developed rich and nuanced understandings of how the therapeutic relationship is experienced from the perspective of the person being treated, and explicates the tacit practices, which shape this experience. This care experience need not be specific to WPTA clinicians. Rather, in this chapter, I expand on how these relational practices may represent humanising practices that all clinicians could bring into the clinical encounter to enhance the experience of care.

Four themes were constructed from the data gathered through 29 interviews ($n = 11$ secondary analysis, and $n = 18$ primary analysis). Theme one, **seeing patients as persons and explicitly acknowledging their unique illness history**, captured the importance of being seen as a person first and acknowledging personhood. It highlighted that people with chronic illness arrive at the consulting room of any clinician with extensive experience of their symptoms, and their encounters with

clinicians and the system. In some cases, past encounters may have actually exacerbated their suffering. This theme brought to the forefront the importance of clinicians' ability and willingness to create the space for the person being treated to bring their whole self, including these experiences, to the therapeutic encounter. The act of doing so contributed to patients' sense of being seen as persons, beyond their symptoms and illness.

Theme two, **clinicians bringing their whole selves into the therapeutic encounter**, captured the subtle negotiation of professional identities, clinical expertise and boundaries within the therapeutic encounter. It highlighted how clinicians who are able to be present as persons, and *see* the person in front of them as whole and as an expert in their own illness experience, created a sense of working alongside the patient. Theme three, **negotiating first encounters**, focused on participants' need to feel listened to and truly heard, before they engage in the WPTA process and *allow* WPTA clinicians to gain access to their *whole*.

Theme four, **a door into understanding**, attempted to capture the essence of what the WPTA experience meant for the participants in this study. This is conceptualised as a profoundly *humanising and transformative educational experience* where participants spoke of gaining an understanding of the connection between their individual biographies, psychological experiences and emotional states, and how these uniquely contributed to their own physical conditions. Understanding these links appeared to offer participants a way out of living a life dominated by their symptoms and condition by offering hope and, subsequently, a sense of freedom.

8.2 Novel contributions to knowledge

This research is the first investigation into the experiences of persons treated in the WPTA by clinicians who are diverse in terms of experience, context of care and disciplinary background. The findings offer a rich tapestry of topics relating to care experiences that will be further explored in this discussion. When considered as a whole, the findings suggest that *being seen* speaks to the experience of truly feeling acknowledged for one's personhood within a clinical therapeutic encounter. Drawing on the metaphor used by Ellis-Hill, Payne, and Ward (2008) in their life thread model, my own visualisation of the experience of *being seen* is one of an intricately woven fabric made of different threads, which represent the tacit, implicit and nuanced acts of communication and relationship-building undertaken by WPTA clinicians, which

resulted in the existential experience of being acknowledged for the whole of one's personhood. My findings suggest that it is through this relational experience that patients were able to gain a profoundly humanising and transformative educational experience regarding the unified nature of their illness.

WPTA clinicians are trained in a non-dualistic philosophical ontology when approaching the treatment of physical illness (Broom, 1997, 2000, 2016b). The findings of this doctoral work suggest that it is their ability to *practise* non-dualistically which may characterise the unique nature, as well as the apparent success, of this approach. The in-depth exploration of the WPTA experience has made it possible to untangle, describe and elucidate these nuanced acts and ways of being-in-relationship. This represents the overarching novel contribution to knowledge this doctoral research makes. It does not constitute a *paint-by-numbers* guide, but rather it is constructed as an invitation for clinical self-reflection, by providing descriptions of the tacitly subtle acts that form the deep communication patterns and relational practices experienced by patients as profound.

I suggest that WPTA offers a unique opportunity to explore the inner workings of these relationships because of the ontology of the approach, which in-and-of-itself necessitates that the clinician attends to the whole person. The benefits articulated by patients of having a transformative educational experience and understanding the mind-body connections, in the specific context of their own lives, were only made possible through the clinicians' ability to co-construct therapeutic relationships with their patients which were experienced as authentic and enabling. This profoundly humanising and transformative educational experience changed the theories and explanations participants had with respect to themselves as persons, their histories, illness and symptoms. Although these findings do not provide a representative authority on behalf of all people treated with WPTA, this research can be seen to provide several novel insights that may be of general relevance to improving the care approaches for chronic conditions. The insights are presented below not in terms of their hierarchy of importance. Rather, I chose to present them in a way that attempts to demonstrate the advancement and progressive extension of my thinking, as I grappled with extending existing literature whilst analysing and interpreting the data.

First, this research further supports the concept of chronic illness as a biographical disruption (Bury, 1982; Charmaz, 1983), and expands this notion by arguing that encounters with medical clinicians and the medical system materially contribute to this

existential disruption. As such, it orients the clinician to acknowledge the existential impact the symptoms *and* treatment to date may have had for the patient. I suggest that patients experienced this acknowledgement as a powerful cue indicating that the clinician recognised their personhood. The next section addresses this contribution to knowledge, and the other key contributions in more depth.

The second novel contribution to knowledge is achieved through transforming the concept of *readiness* to enter into, and benefit from, a therapeutic relationship: from one that is primarily vested in the patient into one which is co-constructed in relationship. In line with contemporary advancements in rethinking clinicians' behaviour and their role in influencing how patients engage in therapeutic relationships (Bright, Kayes, Worrall, & McPherson, 2014; Kayes & McPherson, 2012; Kayes et al., 2015), this doctoral study offers explicit illustrations of the clinicians' role in activating patients' readiness through enunciating the tacit ways of being and acting, which result in patients feeling *seen*. It is the humanising experience of these relationships which appeared to resonate most for participants.

The third contribution this doctoral research makes is identifying what is unique to WPTA from the patients' perspective. To date, the descriptions of WPTA practice have been undertaken primarily by clinicians (Broom, 2016b; Broom & Joyce, 2013; Lindsay et al., 2015). This research has provided deep insights, based on sound methodology, concerning the profoundly humanising and transformative experience patients had when clinicians were able to successfully co-construct the therapeutic relationship and activate their readiness. These were the insights that enabled participants to experience existential freedom and hope about their chronic conditions and/or symptoms. I expand below on how these insights appeared to lead participants to reconceptualise their personhood as it pertains to their illness and even more broadly; in a way, becoming able to disentangle their sense of who they are from the illness and the vicissitudes of their symptoms. Participants spoke of their growing ability to reconstruct a positive identity independent of their symptoms/illness even though they may have still been suffering from those. Throughout this chapter, I chose to include additional quotes which further support the interpretation offered.

8.2.1 Expanding the concept of chronic illness as a therapeutically relevant biographical disruption

Participants described living with worry, fears, anxiety and with a body experienced as unpredictable. These descriptions and their accounts of living a diminished life are

consistent with much research on the experience of persons suffering from chronic illnesses (Ali et al., 2014; Demain et al., 2015; Håkanson et al., 2010; Morales-Asencio et al., 2014; Röing & Sanner, 2015; Tlili et al., 2015). Participants appeared to experience what Bury (1982) described as “chronic illness as a biographical disruption”. Indeed, the first theme, “seeing patients as persons and explicitly acknowledging their unique illness history”, included a sub-theme, which incorporated the concept of chronic illness as a biographical disruption. Bury (1982) argued how the separation of disease from self becomes more difficult in the case of chronic illness. According to Bury (1982), chronic illness involves a person coming to intimately experience worlds of pain, suffering and even the possibility of death, further exacerbated by disruptions to social relationships, with the person who is sick not being able to participate in the “normal rules of reciprocity and mutual support” (Bury, 1982, p. 169).

Much of the literature on chronic illness as a biographical disruption is concerned with the illness experience of the individual, where their former healthy and positive identity crumbles as a consequence of the illness, contributing to a perceived loss of self (Charmaz, 1983). This is echoed by what Ellis-Hill et al. (2008) illustrated with the life thread model in the context of rehabilitation. In this model, the authors brought to light how the predictability of how people undergoing rehabilitation have lived their lives is disrupted as the threads that used to make them –work, study, family and relationships – have been broken or severely limited.

This doctoral research illuminates another element of this disruption, which is largely absent in the literature on chronic illness as a biographical disruption (Bury, 1982; Charmaz, 1983; Hubbard, Kidd, & Kearney, 2010; Williams, 2000). This element is concerned with the impact of the encounters within the medical system, which may in themselves contribute to the experience of an altered life, negative sense of self and loss of identity. Participants described the chaotic journeys they endured, where they felt lost and “handled like a product” moving through “the production line” that is the medical system.

These experiences appeared to be amplified by those medical care professionals that minimised and reduced the legitimacy of these experiences, which exacerbated participants’ suffering, and already-altered sense of self. Participants expressed, some explicitly and some implicitly, their desire to be acknowledged from the beginning by their treating clinicians for all of these difficult experiences, which included the symptoms, subsequent altered life, impact of treatment side effects as well as these

difficult encounters. Some actually worked hard at doing so, as illustrated by Amy describing how she resorted to writing her own referral letter to convey the extent to which the symptoms, and the quest to have them treated and resolved, had impacted on her ability to live her life (see Chapter 6, Section 6.4 for details). In her interview, she was clear how this was almost a “last resort”, as so many of the clinicians she saw did not appreciate the devastating impact of her experiences with the symptoms, and the system, and that she felt she had to take responsibility to communicate “her point of view”.

This phenomenon of working hard to appear credible to a treating physician, by conveying the extent to which the person is impacted by their physical symptoms, mirrors research discussed in Chapter 3. For example, Werner and Malterud (2003) research into the treatment experiences of women experiencing chronic pain, found that their participants reported working hard when consulting biomedical doctors at making their symptoms visible, real and physical, so that they would be perceived as credible patients and receive the care they needed. Similarly, Tarrant et al. (2015) described how people living with complex conditions and multi-morbidity appeared to have taken upon themselves the need to appear as credible patients in order to establish their legitimacy for receiving appropriate care.

This study’s findings also reflect research demonstrating the negative experiences of people with hard-to-diagnose or undiagnosable conditions discussed in Chapter 3. The findings were consistent with contemporary studies which indicate that the most negative care experiences are those of people who suffer from hard-to-diagnose conditions such as systematic lupus erythematosus (Sutanto et al., 2013), and conditions that do not have a clear diagnosis or aetiology, such as chronic Lyme disease (Ali et al., 2014) and IBS (Håkanson et al., 2010).

This doctoral research provided revealing descriptions of these negative experiences from the perspective of the person being treated, illuminating the profound impact these experiences had. The emergent concept of “treatment burden” is a relatively new development towards addressing the treatment aspects of living with chronic conditions (Demain et al., 2015; Sav et al., 2013). Treatment burden concerns “the burden associated with proactively treating and managing chronic illness” (Sav et al., 2013, p. 665) and includes considerations of the “negative impacts of treatment on functioning and well being” (Demain et al., 2015, p. 7). However, in a relatively recent systematic review of qualitative research on this concept, Demain et al. (2015) revealed that the

impact of negative experiences with medical care providers, and the medical system, is not yet explicitly considered as part of research on this topic, although they do acknowledge that the quality of relationships between patients and clinicians could exacerbate or ameliorate patients' ability to adhere to treatment recommendations. Demain et al. (2015) found that it was not the severity of symptoms and side effects that determined how burdensome treatments were, but rather it was the relational disruptions, and psychological and biographical consequences that had the most impact for patients. Indeed, this growing recognition that the burden of treatment on people with chronic conditions should be addressed separately to the burden of the illness itself, has contributed to a growing body of research and policy calling for care to be organised into minimally disruptive medicine (May, Montori, & Frances, 2009). I further suggest that including an expanded conceptualisation of the influential concept of chronic illness as biographical disruption, has the potential of becoming a core component of the argument for minimally disruptive healthcare, including the re-organisation and clinical training necessary to support it.

For the person being treated for physical symptoms, their life's story is now entangled with the story of their illness and the quest to treat it. The experiences of trying to receive appropriate care become integral to the disruption to their personhood. Not only are people no longer able to conduct themselves in the ways they used to, they are also enduring encounters with clinicians that leave them questioning their very core. Clinicians who doubt their symptoms and speak in an opaque manner that makes them feel stupid, operate within a system, which is experienced as chaotic. A novel contribution this doctoral research offers is the expansion of the concept of chronic illness as a biographical disruption to incorporate the experiences with health practitioners and the health system as potentially integral to that disruption. By doing so, the clinical relevance of this concept is enhanced, and the focus is expanded from the individual and their own resources and ability to cope, to include relational and organisational aspects.

In their systematic review, Demain et al. (2015) identified rationalised non-adherence as a strategy employed by patients across the studies to minimise the burden of care and treatment. Patients in those studies made deliberate and rational decisions about not adhering to medical recommendations as a way of minimising the burden of the treatment. Patients did so in secret for fear of being judged or rebuked which, as the authors discussed, could impact negatively on their health outcomes because important

information may have been withheld that could be material to clinical reasoning and further treatment recommendations. The prevailing focus in explaining non-adherence is indeed on the individual's resources and personality, and therefore non-adherence is often construed as sign of the patient's lack of discipline, or personal moral failure (Demain et al., 2015; Tlili et al., 2015). However, if clinicians invite patients to articulate their experiences with the illness and the treatment burden, it may be the case that patients will feel able to answer truthfully, thus enabling clinicians to provide better care.

Indeed, in the present study, clinicians who created the space for people to communicate these disruptions and seemed to appreciate the work associated with chronic illness management were experienced as healing in-and-of-themselves. Moreover, participants were able to openly share with them the impact of their illness as well as of the quest to get a treatment and impact of treatment itself. Indeed, this explicit acknowledgment of the unique life story, as well as illness and treatment history, may have contributed to trust being built between clinicians and patients, and became a foundation on which stronger therapeutic relationships could be established and other aspects could be explored.

Shifting the lens from almost exclusively focusing on the patient, their socio-emotional and psychological resources and ability to cope, to comprehending the clinical encounter as co-constructed within a specific system and organisational culture, invites an examination of the concept of patient readiness in clinical encounters. This is explored in-depth in the following section. This research provides a direct insight into the sophisticated and nuanced practices that clinicians use which activated readiness in their patients. These practices begin with an explicit acknowledgment of patients as persons by attending to all of their history, including their unique illness history and the journeys they have endured in trying to alleviate it.

8.2.2 Reconceptualising readiness

Readiness to enter the psychotherapy-influenced WPTA was one of my three pre-existing assumptions entering the research, and as such was used as a synthesising concept throughout (see Chapter 1, Section 1.3.2). In documenting my pre-existing assumptions, I explicitly acknowledged my belief that readiness in the context of the WPTA goes beyond the concept of readiness to change that is discussed in a number of behaviour change interventions (Peterson, 2009). My rationale was that persons with chronic illness, who are already struggling with the day-to-day reality of their lives,

might have fewer psychological resources to draw on when engaging in this therapeutic approach. As illustrated in Chapter 1, when undergoing chemotherapy, my own resources were focused on managing day-to-day, making my appointments, taking the right medications at the right time, and mothering two young children. I personally did not feel like I had the psychological resources and emotional strength needed for what I perceived as the emotional intensity of the WPTA.

However, through the analytical process, this assumption was transformed from focusing on the role of the individual receiving the WPTA to be ready to benefit from it, to one which concerns what it is that clinicians can and are doing in order to facilitate or activate this readiness. The severity of symptoms did not appear to relate to persons' willingness/readiness to engage in the WPTA. Rather, it was the quality of the relationships established with the clinicians that seemed to determine this. This was consistent with my other prior assumption that the quality of the therapeutic relationship would enable the success of the approach (see Chapter 1, Section 1.3.3), which was the only assumption subsequently supported by the data.

However, I initially construed the concept of quality relationships to be primarily concerned with the ability of the clinician to create a "safe" environment for the patient to engage with the process and bring their whole self into the encounter. This notion of "safety" was not supported by the data. Rather, the findings elucidate the subtle, yet powerfully experienced acts, behaviours and ways of being by clinicians that activated persons' readiness to engage with the WPTA. As a result, the findings offered the possibility of conceptually transforming readiness from being a state that is almost solely vested with the individual patient's capacity for self-reflection, personal insight and their willingness to engage and work on themselves, to something that is negotiated in relationships between the clinician and the person in front of them. Reconceptualising patient readiness represents the second novel knowledge contribution of this doctoral research.

This research suggests that readiness could be construed as co-constructed, where the ways in which clinicians approach the clinical encounter with people who have a chronic illness, could activate the state of readiness of their patients to engage with this therapeutic approach. Through this process, a deep sense of trust is achieved, which is inherent to the success of the relationship. This contrasts with much contemporary literature, which almost singularly focuses on patients' own beliefs, mind states and subsequent actions, which has led to many models and theories developed for the

purpose of providing explanatory mechanisms of the uptake and success of interventions (Ambrosio et al., 2015; Kayes et al., 2015).

Traditionally, research has been preoccupied with patients' state of readiness to engage in care and their ability to care for themselves, as well as the impact of their beliefs on their response to illness, and willingness to work to improve their condition (see for example, Ambrosio et al. (2015) and Griffiths et al. (2014)). The findings of this doctoral research may be seen to reflect a growing awareness within qualitative health research, that re-conceptualises relational clinical constructs, such as engagement, which have commonly been considered as patient-directed, to include and articulate the role clinicians play (Bright et al., 2014). The findings may elucidate the ways in which clinicians' own personal beliefs about the origins of illness are expressed in acts and behaviours which are interpreted by patients and contribute to therapeutic outcomes. These findings provide further support for calls to explicitly consider clinician factors when evaluating and considering health interventions and treatment outcomes (Kayes et al., 2015).

Activating readiness in the context of this research appeared to be enacted in two different aspects of the therapeutic encounter which are discussed in detail below. The first was concerned with the ability/willingness of the clinician to bring therapeutically relevant aspects of their whole selves into the encounter, while seemingly addressing the inherent conflict concerned with retaining their professionally prescribed boundaries. This, rather than the experience of feeling safe, as I had anticipated, seemed to contribute to patients' trust in the clinicians and subsequent willingness to bring their whole selves into the relationships. The second aspect of co-constructing readiness explored in this section is concerned with the listening practice of clinicians. By unpacking what happened in the first encounters which enabled or restricted the development of these transformative relationships, I attempted to illuminate these subtle and powerfully therapeutic practices.

8.2.2.1 Examining clinicians' ability to bring therapeutically relevant aspects of their whole selves into the encounter while maintaining professional boundaries

The findings of this research offer insights into the viscerally different experiences of encounters with rigid professionals who saw themselves as experts first and foremost and contrasts those with experiences with clinicians who saw themselves as people-in-relation with a relevant clinical skill-set. Descriptions of rigid and heavily

boundaried care experiences in the context of the biomedical system are not uncommon. It is widely acknowledged that many medical professionals perceive themselves as experts in relation to those they are treating. As discussed in Chapter 2, these are clinicians who see their role as strictly being about treating the disease and related symptoms which fall under their domain of expertise. These clinicians often do so irrespective of the patient's experience or preference with respect to their own treatment (Charles et al., 2011; Miles et al., 2000; Miles & Loughlin, 2006, 2011; Thorne et al., 2000). This conceptualisation of care, it is said, often results in clinicians configuring the persons receiving the care as passive recipients of information, advice and treatment (Ellis-Hill et al., 2008).

The participants in the current study appeared to be experienced in the health system and sophisticated in sensing if their clinicians were prepared to bring more relevant aspects of their authentic selves into the clinical encounter, in addition to their professionally prescribed identity and clinical skills. This, in turn, appeared to influence the ways in which participants were prepared to trust the clinicians and share their whole selves with them; that is, become willing to engage in WPTA and provide access to their emotional and relational lives and experiences. Clinicians' ability to bring these relevant aspects of their whole selves into the encounter was evident in most of the accounts regarding the WPTA, but was not unique to them. In all cases, this ability and willingness appeared to contribute to the participants' willingness to engage in the relationship and follow clinical guidance and advice, whether it was regarding the mind-body links or any other clinical direction. The findings do suggest that this willingness for clinicians to bring these relevant aspects of themselves into the encounter was more common within the WPTA experience. Arguably, it may be that WPTA clinicians' conceptualisation of illness aetiology and progression as encompassing all aspects of the patient's personhood (Broom, 2002, 2007; Broom et al., 2012) may influence this.

In contrast, participants described encounters with clinicians with rigid professional boundaries who were disease- and symptoms-focused, and who only brought their professional skills into the therapeutic encounters. They described how these clinicians assumed it was their right to control the treatment for participants, and that their patients should just do as they were told. These encounters were experienced as minimising participants' own sense of agency, de-legitimising their willingness to take charge of their conditions, and resulted for some, in starting to doubt their own experience with their own body. These findings are very consistent with those of other research into the

experience of people with chronic conditions, such as the work of Tania Gergel (2012, 2013).

Research suggests that persons who suffer from chronic conditions willingly take responsibility to care for themselves by becoming knowledgeable about their illness, and learning to listen to cues about their own body (Thorne et al., 2000). Indeed, they spend the most time with their own body and symptoms and ought to be seen as experts in their own condition (Phillips et al., 2014; Thorne et al., 2000). Further, many patients want to exercise greater control over their healthcare rather than being the passive recipients of care (Ambrosio et al., 2015; Thorne, Paterson, Russell, et al., 2002). When seen as persons and invited to participate in their own care relationships, participants experienced this as legitimising of their own resources and expertise.

Clinicians who brought authentic and relevant aspects of themselves to bear in the clinical relationship, whilst being sensitive to the patient's needs without burdening them, were experienced by participants as having well-grounded, legitimate and flexible professional identities. Participants described experiencing these clinicians as persons-in-relationships who had a relevant clinical skill-set, but who did not view themselves as having all the answers. Participants described how these clinicians approached them as experts in their own illness, who should be respected and listened to and invited to participate almost as “peers in a way” with their own care decisions.

These behaviours could be seen as an enactment of the Māori¹ concept of *manaakitanga*, the skill of hospitality, which Drury and Munro (2008) adapted in the context of healthcare as a practice of clinicians who create an atmosphere where the *mana*, or status and power of all, in the context of clinical care, is recognised and enhanced. The experience of *manaakitanga* is evident in a participant describing a WPTA clinician as a “friend but not a friend”, indicating that the relationship felt more personal to them, and yet they were aware that it was not a friendship. Drury and Munro (2008) described the Māori conceptualisation of the art of hosting, or *manaakitangata* as involving the ability of the host – or clinician in the context of healthcare – to create an atmosphere where the *mana* of both clinician and patient is enhanced.

One of the key ways in which WPTA clinicians may have been able to create a sense of *manaakitanga* was by carefully sharing more of themselves than what patients have come to expect within healthcare encounters. Throughout the interviews, participants

¹ Māori are the indigenous people of New Zealand.

commented on how relevant and important this deliberate sharing was from their perspective. They also commented on how different the relationship felt as a consequence, because these patients, who described having had extensive experience in the medical system, were able to contrast them with the heavily boundaried care approaches they had also experienced.

WPTA clinicians shared more of themselves in a variety of ways, which *prima facie* may appear to contravene traditional conceptualisations of professional boundaries (Austin, Bergum, Nuttgens, & Peternelj-Taylor, 2006; Nadelson & Notman, 2002). Clarity around boundaries between medical providers and their patients is extremely important and has received much attention. Most of the discourse around boundaries appears to be justifiably concerned with the potential for harm to the patient that may occur when boundaries are violated. There is an emphasis on early attention to minor boundary crossings, such as holding a patient's hand to comfort them, so that they can prevent the occurrence of harmful boundary violations, such as the potential for sexual misconduct (Nadelson & Notman, 2002).

Whilst of course this is necessary and important as a way of preventing the harm that may occur in a relationship where there is a responsibility of trust and care (Nadelson & Notman, 2002), there seems to have been little or no attention given to the impact of experiencing heavily boundaried encounters and the potential harm that may arise from that. Clinician's self-disclosure is extensively discouraged as it is seen as a boundary problem because it risks the health practitioner using the encounter to address their own needs for validation or sympathy (Nadelson & Notman, 2002).

In their paper considering the ethical consequences of the use of the "boundary" metaphor in the context of therapeutic relationships, Austin et al. (2006) argued that the use of "boundary" as the defining metaphor which guides the dimensions of ethical clinical practice is problematic. They articulated how the "boundary" metaphor evokes visions of a solid line between clinician and patient that is straightforward and clear, whereas the reality of the clinical relationship is complex, murky and constantly shifting. Austin et al. (2006) further highlighted the problem associated with having strict rules for practice which assume that clinicians require a set of external rules to adhere to, rather than being guided to mindfully reflect on the ethical dimensions of their practice. Of most relevance to this doctoral research, is the argument that Austin et al. (2006) make that this conceptualisation of concrete boundaries might diminish the humanness of the therapeutic encounter and undermine therapeutic effectiveness.

Austin et al. (2006) go on to offer three alternative metaphors: the “highway”, the “bridge”, and the “territory”. The “territory” metaphor, most relevant to the present research, is borrowed from Canadian Aboriginal elders and refers to a time when there was no firm boundary between tribal lands. Rather, there was a territory, which was a land in-between, to which members of both tribes could travel, with vigilance and mindfulness of the other tribes’ actions. The territory was no-one’s land and it was a safe place as long as both tribes respected it. Austin et al. (2006) proposed this as a better metaphor for conceptualising the ethical dimension of the care relationship, as it denotes a mutuality where both parties “are entering uncharted territory” (Austin et al., 2006, p. 87). In this metaphor, a sensitive practice is called for, and clinicians are guided to consider ethical issues as an ongoing practice, such as sharing of personal and even sensitive information.

The findings of this doctoral research suggest that clinicians’ ability to mindfully share some personal information, which they deem as relevant for the patient’s own journey, appears integral to the patient’s willingness to seek, and benefit from the care relationship. Or put differently, it seems integral to *manaakitanga* being established (Drury & Munro, 2008), where participants feel that their own mana is enhanced. This was illustrated in the findings where a WPTA physiotherapist shared her experience of being hospitalised as a child with Colleen who had endured many childhood hospitalisations herself and was fearful of medical encounters as a consequence. This willingness to share was something that Colleen took as a key signal about the possibility of a different experience with this biomedically trained clinician, and was central to her decision to seek treatment for deterioration in her physical state.

Drawing on the “territory” metaphor (Austin et al., 2006), in the current research, WPTA clinicians mostly appeared to treat the therapeutic encounter as an uncharted territory where the dimensions of the relationship were sensitively explored and negotiated afresh. In illustrating how different metaphors result in different conceptualisation of the same situation, Austin et al. (2006) described a case study of an aboriginal woman, Betty, who suffered domestic abuse and was on the streets. Betty was seeing her social worker weekly to access her welfare payment and described that experience as “playing the game” (p. 89). Austin et al. (2006) described how Betty in one of her visits was shocked to see her white social worker with a black eye, but that what mattered to her most was her social worker’s response when she asked her what had happened; the social worker actually told her that her husband hit her. Austin et al.

(2006) described how transformative this experience was for Betty as she now was able to see both the social worker and herself in a new way. Like Colleen in the present study, it was this thoughtful and relevant personal sharing by the clinician that was key to Betty deciding to engage with her social worker. Betty has since become a mental health worker herself. Austin et al. (2006) proposed that using the “territory” metaphor means that the therapeutic relationship is established in a shared space where both the clinician and the person are able to reside safely. Unlike the “boundary” metaphor, which presupposes what can and cannot be shared, the “territory” metaphor calls for active and continuous reflection on the consequences of sharing this kind of personally revealing information.

In the context of this study, the successful relationships established between WPTA clinicians and the people they were treating can be conceptualised as one where a territory, a new shared space, is established, where both clinician and patient negotiate how they interact, but where the WPTA clinician takes more of an active role, being a host of sorts, enacting *manaakitanga* for their patients. Where successfully established, the WPTA relationship was experienced as mutual in that the clinician and patient did something together that neither could have done separately. This mutual relationship allowed them each to be more human with one another (Kaplan, 1994). Participants acknowledged that the clinician was not their friend, but they felt that they were on their side and that they were both working together to achieve an outcome, rather than the clinician having all the answers and the patient being expected to just obey and follow (Ellis-Hill et al., 2008).

This experience of humanness and mutuality echoes the conclusion of Thorne et al. (2005) who argued that “being or not being known” in the context of cancer care is a useful conceptual construction that can be helpful in interpreting how cancer patients responded differently to clinicians in discrete communication encounters. Indeed, in this doctoral study, participants also contrasted their experiences of being looked at – an experience where the clinician was doing something *for* and *to* them – with the experience of “being seen” – an experience of humanness and mutuality where both were doing something *together*.

I suggest that the ways of relating to patients described in this study, may be an enactment of the non-dualistic, ontological assumptions held by WPTA clinicians about the origins of their patients’ conditions (Lindsay et al., 2015), which allowed patients to do the same after years of not being supported to view their conditions in this unified

way. It has been suggested that the theoretical orientation and beliefs of clinicians influences their clinical approach to working with patients (Kayes et al., 2015). The findings from this study suggest that these WPTA clinicians, with their unified beliefs of symptom aetiology, operated in a shared territory with their patients (Austin et al., 2006), while appearing to mindfully retain their professional identities. Consequently, they were experienced as less rigid and therefore, their ability to be with their patients was enhanced (Cloete, 2013). As a consequence, these clinicians were more able to *see* and *know* their patients. The clinical ability to retain boundaries for the mutual safety of clinicians and their patients but doing so in a flexible way, required a nuanced and sophisticated practice. The examination and the unpacking of how patients experienced listening, offers a way for unpacking the tacit dimensions of this practice.

8.2.3 Unpacking listening

The importance of the clinician–patient relationship in the context of chronic illness is so well documented it might be seen as ubiquitous (Cocksedge et al., 2011; Frederiksen, Kragstrup, & Dehlholm-Lambertsen, 2009; Kayes et al., 2015; Phillips et al., 2014; Thorne et al., 2000). The desire by patients with chronic conditions to be treated as persons by clinicians has been extensively documented elsewhere (Kayes et al., 2015; Thorne et al., 2005; Thorne, Paterson, Russell, et al., 2002; Thorne et al., 2000). It is also well documented that the experience of being listened to, or not being listened to, is key to quality therapeutic relationships as “therapeutic relationships cannot be effective without listening to people” (Ellis-Hill et al., 2008, p. 155). Listening in the context of healthcare relationships has also been related to the ethical dimensions of the care relationship (Davis, Foley, Crigger, & Brannigan, 2008).

In this section, I focus on aspects of the listening practice, within the context of WPTA, which appeared important in the process of transforming readiness to something that is done in relationship. These listening practices correspond with the three sub-themes observed throughout the data set: “the art of listening”, “the act of listening” and “the heart of listening”. It may be interesting to reflect that the importance of the experience of being listened to was not one of the assumptions I made at the outset of this study.

Commentary about the importance of listening in clinical contexts is becoming more prevalent. For example, Kagan (2008) suggested that persons treated by health professionals most commonly complain about not being listened to, and desire the experience of being listened to, more than anything else in the therapeutic encounter. It is also widely acknowledged that listening in the context of healthcare is an essential

element in patient satisfaction (Davis, Thompson, Foley, Bond, & DeWitt, 2008). Further, it is argued that listening is much more than hearing, as it is about the intent, and the practice of being truly present (Bunkers, 2010). In a recent autoethnography by clinical researchers, the primary strategy the authors perceived in working differently with clients with traumatic brain injury, was active and mindful listening, which they construed as a therapeutic tool in-and-of-itself (Bright, Boland, Rutherford, Kayes, & McPherson, 2012).

However, much of the writing on listening has been written from the perspective of the clinician or theoretician as to what and how listening *ought* to be enacted (Bunkers, 2010). With very few exceptions (such as Bright et al., 2012), there is little articulation of how listening is in fact enacted in the therapeutic encounter, and how it is experienced by the patient (Kagan, 2008). This doctoral research provides an in-depth articulation of the powerful experience of patients feeling truly listened to, which offers concrete yet non-prescriptive invitation for clinical self-reflection.

In this research, WPTA was introduced to the clinical encounter in traditional biomedical settings such as hospital day clinics, and physiotherapist's clinics. This is because the sampling approach undertaken in this research specifically targeted participants who encountered the WPTA clinicians in these settings. As the findings demonstrated, some participants described experiencing the first encounter in this context as a "shock". The shock was attributed to hearing a mainstream and medically trained clinician suggest the notion that their lived experiences, as well as psychological and emotional states, may have contributed or even be at the root of the biological processes underpinning their illness. And in one case specifically, a participant described how she initially interpreted the approach as indicating that she was literally making herself sick.

As a consequence, the acts, gestures and techniques with which WPTA clinicians co-constructed the therapeutic relationships, especially in the first encounters, were seen to play an integral role in facilitating persons' readiness to engage in this non-conventional way of being treated. This study does not offer a recipe-book style listening practice recommendation. Rather, through reflecting on participants' rich accounts, and through the process of closely examining practice descriptions, it offers a glimpse of the many and varied practices and ways of being, employed authentically by WPTA clinicians, which resulted in patients' experiences of feeling listened to. These were the experiences which may have consequently transformed participants into being *willing*

and *ready* to be treated in this way. This appeared to be the case irrespective of how *psychologically minded* the individual was initially. Psychological mindedness (Appelbaum, 1973) is a frequently used psychotherapeutic term that is concerned with people's capacity for reflectiveness, self-observation, and self-awareness, or the ability of an individual to reflect on her or his internal life. It is seen as an important patient-factor for psychotherapy's success (Appelbaum, 1973). The findings of this doctoral research do suggest that when an individual may have been less *psychologically minded* to begin with, the focus on listening and being in relationship might have been even more crucial to their willingness to eventually engage.

The findings of this study are consistent with the idea that listening is a values-based clinical practice, influenced by how clinicians conceptualise their practice and their own professional role within it (Bright, 2015). It also offers illustration of practices that resulted in patients feeling not listened to, which led to them consequently acting in what could be construed as a resistant manner.

The importance of this listening practice for facilitating readiness can be demonstrated by Jason's description of his initial resistance to the WPTA following his first encounter with a WPTA clinician who he experienced as not listening, because she cut him off when he was trying to tell the story of his symptoms and treatment. He experienced her as wanting to focus on his *relational story* when he was not ready to share or engage in this way. Rather, his interview suggested that at the outset, Jason needed the WPTA clinician to focus on the ways his symptoms had affected his life and visibly work to address these. In contrast, the impact of feeling truly listened to, as materially facilitating readiness, is illustrated in the interview with Lorie, who described how resistant she was to the WPTA initially, and how, through the listening practice of her WPTA clinician she "*eventually gently accepted the fact that my mind and body are connected*".

Allowing time and space for patients in a time-limited clinical encounter to communicate what is important to them, may feel unrealistic and even unprofessional for clinicians who operate from within a medical system that prioritises stringent, efficient and effective use of resources. However, this research suggests that WPTA clinicians were able to do so in ways that were experienced as therapeutic by patients. These findings mirror those of Bright et al. (2012) who described in their co-autoethnography how they found that they were able to discipline themselves to learn how to listen. Bright et al. (2012) were able to provide the space for their clients to lead

the process, and although the focus on talking and listening rather than *doing* in the context of rehabilitation felt strange, they came to consider active listening as a therapeutic tool, that if done well, resulted in rapid progress as clients became more engaged. In the current study, it is suggested that the WPTA clinicians with their own non-dualistic ontology, were also able to discipline themselves to listen carefully within the restrictions of the predominantly biomedical environments in which they operated.

Much of the writing on listening emphasises certain characteristics, which are common across multiple disciplines from business, through education and healthcare, such as empathy, being able to attend to verbal and non-verbal communications, as well as being experienced as non-judgemental and accepting (Shipley, 2010). However, there are few in-depth investigations of how these are enacted in the clinical encounter from the perspective of the person being listened to. In her phenomenological enquiry into the experience of feeling listened to in the context of healthcare encounters, Kagan (2008) concluded that when reflecting on her participants' accounts, she constructed the experience of feeling listened to "*as nonjudgmental acknowledgement that occurred rarely*" (Kagan, 2008, p. 63). However, Kagan (2008) stopped short of exploring what it meant to be listened to without judgement, and how it could be enacted by clinicians.

The analysis suggested that participants in the present study experienced this non-judgemental listening frequently within the WPTA encounters. It further offered an elucidation of how this practice was enacted and how patients observed and experienced it. Participants observed and noted physical gestures and mannerisms that invited them to speak, and described how these subtle behaviours assured them they were indeed being listened to. Drawing on Bright et al. (2014) reconceptualisation of engagement, I propose that these behaviours signalled to patients that the clinicians were authentically engaged in the therapeutic process and were actively seeking to engage with the participants as people.

In the present study, being listened to was especially experienced when clinicians actually engaged and did not *just* listen passively; a sub-theme I named "the act of listening". Active/dynamic listening is not a new concept and strategic questioning has long been advocated by using strategies such as encouraging looking at many possibilities, avoiding "why" questions, and being respectful and attentive listeners (Bunkers, 2010). In this research, participants spoke of clinicians asking very broad questions, reflecting with curiosity on the information they shared with them, and sometimes telling related stories. This active, dynamic listening was experienced as

powerful, and participants drew on these experiences to determine if the clinician was indeed “really listening” and willing to engage in a mutual person-to-person relationship with them.

However, the experience of being listened to without judgement is something different again, because in the present study, it has been constructed as something more than the absence of judgement. The sub-themes of “the heart of listening” and “observing and acknowledging” enunciated the experience of being listened to in this non-judgemental manner. The heart of listening illustrated the patient’s experience of feeling able to convey the story they wanted to share in relation to their illness, without being *pushed* to focus on particular aspects that *fitted* with the clinicians’ own narrative about their illness. This agenda-less listening can be seen as something quite different from being non-judgemental. The clinician may not at all judge the person in front of them, and yet, because of time constraints, or professional conviction about the origin of the illness, may want the person to focus on aspects of the illness they deem as relevant for their ability to treat. Although no judgement may be present, patients, as articulated in the present research, may still feel as if they are not being listened to, or acknowledged, and therefore may be less willing to engage in the therapeutic encounter.

The sub-theme of “observing and acknowledging” was especially prevalent within the encounters with WPTA physiotherapists who, often in the first encounter, observed and acknowledged how aspects of the person’s biography or other aspects of their personhood might relate to their physical symptoms. They did so without any suggestions or expectation that now the connection has been made, patients should address/resolve/fix those connections. Participants articulated this experience as non-judgemental and extensively commented on how positively they experienced it. This experience can be illustrated with Colleen’s accounts of feeling “*allowed*” to bring all of her story into the WPTA physiotherapist and feeling listened to in an embodied way that allowed her to “*open up*”. Similarly, in a phenomenological enquiry into the experience of feeling listened to, an example was given where one participant (Kim) described the experience of feeling listened to, as an embodied experience where her body responded in expressing “very openly and freely” (Kagan, 2008, p. 61).

The experience of feeling listened to has been described elsewhere as “consistent with the idea of powering” (Kagan, 2008, p. 64) and could be a further illustration of the practice of *manaakitanga* which enhances the mana of patients (Drury & Munro, 2008). This was not limited to those clinical contexts which mainly involved an oral exchange,

such as the immunology day clinic. The powerful experience of being listened to by physiotherapists who are traditionally conceptualised as body clinicians (Nicholls & Gibson, 2010), offers a further novel contribution made by this study. Arguably, the introduction of the WPTA might have been experienced as a *shock* by some participants who sought body practitioners such as physiotherapists for their chronic conditions. And yet, this was not the case. The findings suggested the profound therapeutic experience of being listened to, while being touched by a clinician who mindfully negotiated their professional boundaries so that they could be in relationship with their patients.

This section explored the second novel contribution to knowledge offered by this research which is the transformation of the concept of *readiness* to enter into, and benefit from, a therapeutic relationship: from one that is primarily vested in the patient, into one which is co-constructed in relationship. This was done through an in-depth exploration of two overarching themes: clinicians bringing relevant aspects of their whole selves into the therapeutic encounter, and negotiating first encounters through subtle yet profound listening practices. The implications for the humanness of the encounter of strictly adhering to professional boundaries was explored in depth and other conceptualisations of negotiating professional roles were offered. The listening practices of clinicians, which the findings suggested were key to the process of facilitating persons' readiness, were examined and expanded in relation to contemporary literature.

8.2.4 Illuminating the profoundly humanising and transformative educational experience of the WPTA

The third unique knowledge contribution this doctoral study offers concerns the profoundly humanising and transformative understandings experienced by participants regarding the unified nature of their illness, once the therapeutic relationship was successfully established. I suggest that through this experience participants were able to reconceptualise their personhood as it pertained to their sickness in ways that have led them to experience existential freedom from their illness, and regain hope for their lives.

As described in Chapter 1, coming to understand that my story/history was inextricably connected to my illness was the most powerful part of my own WPTA experience. Consistent with writings on the WPTA, I came to see my illness as “meaningful” in the context of my life (Broom, 2000, 2002, 2007, 2010, 2016b; Broom & Joyce, 2013). I also described how powerful I found the concept of somatic meanings (Broom 2007)

and how I learned to listen to my body through reflecting on those. As a consequence, throughout the analysis I used the *story* element of the WPTA as a sensitising concept. This concept guided the development of increasingly complex questions asked of the data, and culminated in the analytic memo exercise.

However, despite my own powerful experience of seeing my own illness as meaningful in the context of my story, this was not as evident in the data. The meaningful aspect of a particular story as it pertains to understanding illness and symptoms did not emerge as key to the experience of participants in the current study. Rather, for participants, it was the profoundly humanising relational dimensions of the therapeutic experience that were paramount, as these were experienced as a foundational recognition of their very personhood.

Participants did use powerful metaphors, but these were used to articulate the essence of the WPTA experience from their perspective. Throughout the analysis, participants used metaphors such as “*connecting the dots*” and “*opening doors into understanding*” to describe what the WPTA experience meant for them. Initially, I interpreted these to mean that the experience may have invited patients to access their own non-dualistic understandings of their illness, thereby enabling them to activate their own resources, which led to a greater sense of agency in relation to their illness.

Over time, however, I have come to view these metaphors as encompassing both this more pragmatic interpretation, as well as a more existential expression. Thus, connecting the dots became connecting the dots of multiple life dimensions that resulted in a different picture of how they saw themselves. Understanding the connections between mind and body, and how they specifically manifested for them, irrespective of a particular narrative or story, was therefore pragmatically experienced as offering a way to proactively put in place strategies and behaviours which could mitigate “flare-ups”. It may have also been existentially experienced as a way of reconceptualising *who* they are.

Therefore, for participants, this profoundly humanising and transformative educational experience was more than “coming to rest more existentially with **how** things are” (Dahlberg et al., 2009, p. 268) with respect to their condition. This experience appeared to result in them existentially reconceptualising *who* they are, so that they were able to gain a sense of freedom and hope. Their descriptions illustrated a sense of enhanced agency with respect to their conditions and life more broadly. For example, Beth spoke

of trusting in herself to know when to remove herself from stressful family situations, as she learnt that these could lead to having an attack. To be able to do so, she had to reconceptualise her sense of what her role in the family was. Lorie, who was initially very resistant to the notion of the mind-body relationships, described how, despite her original distrust of the approach, the relational ways of her clinician enabled her to come to a very different conceptualisation of her illness. This resulted in her having an increased understanding of how personal and professional difficulties in relationships had contributed to her symptoms, and subsequently reconceptualising her professional identity. As a consequence, participants spoke of being able to live a life not dominated by the vicissitudes of their symptoms or illness. This was the case even if the illness or symptoms were not “cured”. Like me, they too spoke of their illness no longer dominating life as they lived it. I suggest that both the relational dimension and the content of the WPTA operationalises what Dahlberg et al. (2009) refer to in their lifeworld-led model of care in accommodating the essence of being human in the care relationship.

This profoundly humanising and transformative experience seems to have resulted in a reconceptualised sense of personhood. However, with the exception of Beth, with her powerful story of abuse which co-occurred with the onset of her symptoms, other participants spoke of many different “stories” or of none at all. For this study’s participants, the WPTA experience was profound and freeing, but for most, it was not related to a particular life narrative or to their ability to comprehend and reflect on somatic metaphors in their own context.

WPTA clinicians from different disciplinary backgrounds achieved this experience for their patients through different routes once the mutual therapeutic relationship was successfully co-constructed. In the immunology department, it was done mainly through a psychotherapeutically influenced talk-and-listen approach. Physiotherapists achieved this through focusing on breathing, touch and observing and reflecting on patterns of movement. Across the data, it was the quality of the relationship established that determined the success of the approach. Put simply, it was the *how* of being in relationship, rather than the *what*—or the specific technical content of the relationships—which was central to the transformative and humanising experience, as well as beneficial outcomes, reported by participants.

It is relatively well established that a strong motivator for people who suffer from chronic and life altering conditions to seek Complementary and Alternative Medicine

(CAM) is their interest in contributing to their own self-healing by improving their psychological and overall physical wellbeing (Thorne, Paterson, Russell, et al., 2002). Thorne, Paterson, Russell, et al. (2002) also identified how people with chronic conditions employed a strategy of “body listening” as a process of paying attention to how they physically and psychologically responded to therapeutic approaches. I suggest that through the educational experience of the WPTA, this “body listening” practice might have been utilised by participants, and was expanded to include psychological, social and emotionally related states and experiences.

I also suggest that the experience of being recognised for one’s personhood, through these subtle and skilled relational practices, may have also enabled clinicians to successfully introduce new ways of conceptualising illness, health and notions of personhood. Successfully communicating ideas that fundamentally challenge long-held beliefs is complex and often unsuccessful (Stacey, 2003). When simply told that their condition could be related to relational dimensions of their lives, participants like Jason reacted negatively. This study adds to a growing body of research that demonstrates that effective communication cannot be a top-down, linear process, but rather is complex and nuanced (Jordan et al., 2009; Stacey, 2003; Suchman, 2006). It further demonstrates that the success of communicating new and potentially confronting ideas is determined by the quality of the relationship between those who are communicating. One possible theory that may serve to explain how these subtle communication practices have contributed to these profound shifts in understanding is the “complex responsive process theory” (Stacey, 2003).

Derived from complexity science, the complex responsive process theory (Stacey, 2003) stipulates that relationships emerge in partnerships, and that little changes in relationships or the introduction of new themes in communications may amplify and spread, transforming these relationships into new, self-organising patterns, which can be further amplified, and so forth (Suchman, 2006). Here, communication as it pertains to educating and influencing individuals to form new understandings, is not seen as fixed, rule-bound and linear from the expert to the patient (Stacey, 2003). Rather, complex responsive theory stipulates that communication is a phenomenon that emerges between individuals in a non-linear way which leads to the co-creation of new, novel patterns of meaning and relating (Jordan et al., 2009). These novel and new patterns of ideas and meanings develop irrespective of an explicit and directive intention at the outset of the interaction. And, it is suggested, that in trying to force such structures at the outset, one

might actually prohibit those from emerging and undermine efforts to generate change (Jordan et al., 2009). The complex responsive theory appears to speak to the essence of *having an educational experience*, rather than the experience of *being educated*.

The findings appear to suggest that when WPTA clinicians entered the therapeutic relationship with an agenda to pursue a particular mind-body connection, through listening for a particular story that may explain the symptoms, or when the person being treated perceived them as doing so, the therapeutic experience was seen as unsatisfactory and even harmful. As explained in the introduction, the WPTA is concerned with shifting the ways in which persons with chronic conditions conceptualise their illness. But as the findings demonstrate, introducing this non-dualistic conceptualisation of health and illness to people who are suffering from chronic conditions can be experienced as unsettling and even upsetting if done without the therapeutic relationship being sufficiently established.

Within the context of contemporary dualistic and mechanistic conceptualisations of health and illness, any suggestion by a treating clinician that physical symptoms may be directly related to other *life-dimensions* is likely to be interpreted by the patient as a suggestion that it is “all in their heads” (Wolfe & Walitt, 2013). Therefore, the centrality of the quality of the relationship with the WPTA clinician, viewed through this lens of relating being a complex responsive process, can be seen as enabling successful negotiation of this *uncharted territory* (Austin et al., 2006). The subtle yet powerful relational practices, described by participants in the present study, appeared to stir these meaning-making patterns in positive directions where the person being treated could reflect and elaborate on them privately so that their impact was compounded.

Complex responsive theory has been proposed as a theoretical confirmation for the principles and practice of relationship-centred care. It is seen to offer a way of making sense of the relational dynamics that underpin that approach (Suchman, 2006). It is growing in popularity in contemporary health research as it provides a theoretical framework in applied health contexts, such as intervention evaluation (Jordan et al., 2009), and understanding physicians’ experiences of patient-centred care rounds (Baathe et al., 2016). It is argued that complex responsive processes of relating provide a way of transforming the traditionally hierarchical relationships in healthcare to partnerships that could hopefully enable new understanding to emerge and be embedded (Suchman, 2006).

In the context of the present study, complex responsive process theory may provide a useful theoretical lens as it focuses on the central importance of conversations which could be difficult and confronting, to facilitating shifts in the ways patients see and understand their own health (Baathe et al., 2016). It stipulates that these conversations are central to the emergence of new ways of thinking and relating, but because they are new and can even be seen as controversial, they can give rise to patients' anxiety. For these conversations to open up the space for these new patterns of meaning-making to emerge, trust is essential (Baathe et al., 2016). This doctoral research offers a unique knowledge contribution by explicating and illuminating the ways in which clinicians enact the relationship-building practices which created a space for these new patterns to emerge.

The findings suggest that when done well, participants continued to reflect on these new patterns, build on their educational experience and construct new understanding of their own health after the therapeutic relationships had concluded. For example, in his interview, David reflected on the allergies he used to suffer as a teenager (not the condition he was being treated for at the time of the interview) and how, through experiencing the WPTA, he had come to see them as relating to his life circumstances at the time, given their onset regularly coincided with going back to a school he hated. Others like David spoke of these new understanding of health and illness and how these kept developing for them after concluding the WPTA treatment experience.

Arguably, it was the relational practices of the WPTA clinicians that opened the way for these shifts in understandings, and new ways of thinking about illness to emerge. These relational practices may have been developed by WPTA clinicians in this research because of their emphasis on listening for patients' whole stories (Broom, 2000, 2002, 2007, 2010, 2016b; Broom & Joyce, 2013). However, from the perspective of the person being treated, this profoundly humanising and transformative educational experience was made possible through the co-constructed mutual relationship which resulted in them feeling that their whole personhood was acknowledged. At least for the participants in the current study, this experience occurred irrespective of a cognitive realisation that the illness was meaningful in the context of their lives.

8.3 Strengths and limitations of this research

There are some limitations to this research that must be acknowledged. The findings of this research are highly contextualised. First, all the clinicians from whom participants

were recruited were highly experienced WPTA clinicians (see Methods chapter for details). Therefore, their clinical practice can be considered exemplary and not necessarily reflective of all WPTA clinicians. Second, within one setting (the immunology department), the WPTA clinicians had a unique context whereby they benefited from having a cluster of three clinicians working in this way. It is possible that these clinicians may have practised within an environmental context which was more supportive and enabling than other biomedical environments. As such, caution should be exercised when considering the direct transferability of the findings to other clinical contexts.

It is also important to consider which voices were not present in this study. Despite utilising purposeful sampling to recruit an ethnically diverse sample reflecting New Zealand's growing ethnic diversity, the diversity of participants remained limited. Unfortunately, I was unable to recruit any Asian participants. It might also be suggested that the number of participants interviewed was too small, given the ubiquitous positivist ontology and quantitative research paradigms in health sciences. I acknowledge that this study may have been strengthened if I was able to explore the insights and perspectives of participants from a wider range of ethnic backgrounds more representative of those seen in routine care in Auckland.

A further important limitation concerns my personal closeness to the research topic, as documented in Chapter 1. Despite the various reflexive strategies I have utilised to transparently account for my own personal experience as a patient, it could still be the case that my own experience continued to influence the research in implicit ways. Arguably, the focus on the therapeutic relationship and experience in the system may have been over-emphasised because of my own experiences.

Various strategies were utilised to ameliorate these limitations. The purposeful sampling process did result in participants from a wide range of ages (18 to 84 years), and I was able to recruit participants from a variety of cultural backgrounds, albeit limited, including one for whom English is a second language. The use of secondary analysis, as well as the theoretical sampling approach which led to include persons who saw WPTA physiotherapists, may have enhanced the *information power* of this research.

Information power is a concept proposed by Malterud, Siersma, and Guassora (2015) for guiding decisions regarding adequate sample size in qualitative studies across a range of qualitative methodologies. The authors argue that sample size decisions in qualitative studies depend on the narrowness or broadness of the research question, the

specificity of sample characteristics required, the presence or absence of theoretical background, the quality of interview dialogue and analytical approach. In this research, the information power may have been enhanced through the diverse characteristics of the participants, and the quality of the interview dialogues which resulted in a broad range of the experiences described by participants (Malterud et al., 2015)

Contributing to this study's strengths is that I used multiple strategies to remain reflexive throughout the study (Malterud, 2001; Thorne, 2008; Thorne & Darbyshire, 2005; Tracy, 2010). The reflexive practice began with detailing my pre-assumptions in Chapter 1, through to providing examples of reflexive memos in the findings chapter, using my own voice as an interviewer in Emily's story and commenting throughout this discussion on whether the pre-assumptions were supported or not by the data. I would also argue that my ability to reconceptualise the notion of "chronic illness as a biographical disruption" by incorporating care experiences and system experiences, was possible because of my own sensitivity to these encounters. My empathy with the participants, because of my own experiences, may have enabled them to share their experiences with me with such openness. I have also attempted to ensure the rigour of the analysis (Malterud, 2001; Sandelowski, 1993; Tracy, 2010; Thorne, 2008), especially in light of my emotional closeness to the research topic, by providing detailed descriptions of the methods in Chapter 5 as well as by making available the sequential analytical process with illustrative examples in Appendix S.

Another strategy utilised was extensively using participants' own words wherever possible. This was done in the findings section as well as in the constructed vignette, to illustrate the strong and clear communication achieved between the participants and myself (Malterud et al., 2015). Indeed, Malterud et al., (2015) emphasises the co-constructed nature of the interview, and how the value of the empirical data depends on the interviewer's skills. They further suggest that in qualitative studies, the quality of the findings depends on the articulateness of the participants, and the chemistry in the interview. With the inherent limitations of using interviews as the primary instrument for data collection, because of the ways interviewers shape which aspects of the phenomena under study are revealed by the interviewee and how they are revealed (Thorne, 2008), I suggest that the data collected were enhanced because of the care utilised in designing this research, as well as my personal background as a patient, and professional background as an executive coach and facilitator. Therefore, quality in this research was enhanced through the use of thick descriptions in the findings chapter and

in Emily's story which was constructed in part to enhance resonance (Tracy, 2010), as well as credibility and findings fidelity (Tracy, 2010; Sandelowski, 1993).

In summary, through acknowledging the limitations inherent in this study's design, and the strategies undertaken to ameliorate them, the findings offer insights from the perspective of the person being treated, that could be seen to provide a possible framework for clinicians to self-reflect on the ways they could establish high quality care relationships with their patients. Through these descriptions, this study offers an enactment of how, when these relationships are successfully established, patients feel *seen* and describe a profoundly humanising and transformative educational experience.

8.4 Implication for practice

As outlined in this chapter, the unique knowledge contributions of this research primarily stem from it being the first of its kind to investigate, in depth, the experiences of persons treated in the WPTA. The experience of *being seen* speaks to the tacit, implicit and nuanced acts of listening, communicating and relationship-building practice undertaken by WPTA clinicians. These resulted in the existential experience of being acknowledged for the whole of one's personhood. Through these nuanced relational practices, clinicians enabled a *co-construction* with the person of a readiness to enter into, and benefit from the profoundly humanising and transformative educational experience the WPTA offers. This educational experience resulted in a reconceptualisation of patients' personhood as it pertained to their symptoms, which in turn appeared to contribute to a sense of hope and freedom. Therefore, findings from this doctoral research offer novel and deeper understanding of the importance of *how* clinicians practice within a therapeutic relationship which may be equally, if not more influential for patients' descriptions of therapeutic outcomes than the *technical content* of the therapeutic approach. This doctoral research has provided further granularity to Engel's words in his seminal article on the biopsychosocial model of medicine (1977), suggesting that:

Even with the application of rational therapies, the behaviour of the physician and the relationship between patient and physician powerfully influence therapeutic outcome for better or for worse. These constitute psychological effects which may directly modify the illness experience or indirectly affect underlying biochemical processes, the latter by virtue of interactions between biochemical processes implicated in the disease. (p. 132)

My findings indicate that the experience of *being seen* for one's personhood occurs in relationships, and is independent of the content of the therapy. However, arguably the content of therapy may help orient the clinicians towards this existential acknowledgement of their patients.

The non-dualistic content of the WPTA specifically orients clinicians towards acknowledging their patients' personhood as clinically relevant in treating physical symptoms. Clinicians who are focused on biomedically treating symptoms may have few prompts or reasons (outside of shared humanity) to see the relevance of acknowledging the personhood of their patients, nor attempt to do so. Accordingly, this research offers a number of practice implications, which arise from the three substantive novel contributions discussed within this chapter:

1. Supporting the concept of chronic illness as a clinically relevant biographical disruption and expanding it to include encounters with medical clinicians and the medical system as materially contributing to this existential disruption.
2. Transforming the concept of *readiness* to enter into, and benefit from, a therapeutic relationship, from one that is clinically seen as primarily vested in the patient, into one which is *co-constructed* in relationship.
3. Identifying what was unique to the WPTA from the patients' perspective - the profoundly transformative educational experience and resulting insights that enabled participants to experience existential freedom and hope from their chronic conditions and/or symptoms, which, I argue, have led them to reconceptualise their sense of personhood as it pertains to their illness.

Drawing these together, I propose that the existential experience of *being seen* may have facilitated patients' readiness and activated their own resources to benefit from the transformative educational experience offered by the WPTA. This research offers insights into the behaviours and ways of being which are experienced by patients as humanising and therapeutic in-and-of-themselves, and which arguably, could activate patients' readiness to benefit from any type of therapeutic approach (Blow, Sprenkle, & Davis, 2007).

8.4.1 Practice implications of considering biographical disruption

Acknowledging the patient's history, including the story of their illness as a biographical disruption of their personhood, is one illustration of this humanising

practice. The research reviewed in Chapter 3 highlighted the negative attitudes medical professionals demonstrate towards persons with hard-to-diagnose conditions or conditions without a diagnosis or a clear aetiology, which contribute to the disruption experienced by patients (Håkanson et al., 2010; Sutanto et al., 2013).

Clinicians who are concerned with working with the whole person might wish to attend to these negative, previous treatment experiences as part of their consideration of the patient-as-person, alongside their consideration of the symptoms and related impairment. In the specific case of the WPTA, clinicians may want to attend to the impact of these experiences as part of their consideration of the patient's relational life more broadly. From the perspective of the person being treated, the experience of being given the space to bring their history, including their illness history, into the therapeutic encounter is experienced as humanising and as recognition of their uniqueness.

Clinicians might also consider attending to the ways patients take the time to enunciate how the illness has affected them, as well as previous encounters with other clinicians, as a cue for self-reflection. This may be a helpful way of reframing how they respond to patients who clinicians may have traditionally experienced as complaining, or as difficult, or even as "heart-sink" (Tarrant et al., 2015). Past experiences of healthcare are arguably formative of how patients engage in subsequent encounters. Therefore, having a sense of their patient's prior experiences, explicitly acknowledging them and being aware of how those experiences may inform the patient's beliefs and expectations, may be a useful tool for clinicians.

As illustrated earlier in this chapter, patients make deliberate and rational decisions about not adhering to medical recommendations as a way of minimising the burden of the treatment and do not disclose these decisions to their treating clinicians for fear of being judged (Demain et al., 2015). Further, in a recent qualitative study of people with multiple chronic conditions aimed at identifying the factors these patients drew on to lessen their treatment burden, Ridgeway et al. (2014) identified positive aspects of healthcare as one of these key factors. Ridgeway et al. (2014) report how good instances of communication and relationships lessened the burden. Interestingly, in one of the quotes used for this theme, the participant also explained the impact on information sharing of having a negative care relationship:

Someone that you're not on good terms with, you have to come see them when it's time to come visit them. And things that you should be telling, you're not

telling because you and this doctor don't have a good relationship. (Ridgeway et al., 2014, p. 345)

It is possible that having once experienced this kind of relationship, a patient may be less likely to communicate fully in subsequent encounters. One way of working to mitigate this type of negative experience is self-reflection. Self-reflection is increasingly advocated for medical professionals as a way to improve the relational aspects of their care (Ekman & Krasner, 2017). However, many of the barriers for embedding self-reflection as part of care are associated with time restrictions and the impersonal stance advocated in many medical and nursing schools (Ekman & Krasner, 2017). A reconceptualisation of biographical disruption to include the impact of care may offer a way for clinicians to reflect on their own practice within the encounter.

I suggest that as medical-history taking is integral to every routine encounter, this routine activity could be transformed by attending to these dimensions of the person's illness story. Mindfully attending to the ways patients describe their illness journey becomes more than *just* letting patients air their grievances so that the clinician can *get on with it*. It can become a humanising activity that signals to patients that their personhood is recognised. Further, clinicians may reconceptualise this routine activity as an ongoing reminder of their impact on patients, and therefore this could facilitate an active shift in how they relate and engage with the person they are treating.

8.4.2 Practice implications of transforming a patient's readiness into a co-constructed construct

Transforming the routine activity of history taking into an activity that can help clinicians *see* the personhood of their patients may be the beginning of a process that facilitates patients' readiness. A further resource that this research offers is the description of practices used by clinicians that were perceived to build quality relationships that had the capacity to facilitate patients' readiness. I suggest that these practices were also concerned with recognising the personhood of the patient and that this research offers ways for clinicians to reflect on how their practice impacts on their patients' readiness to enter into, and benefit from, a therapeutic encounter. Reflecting on practice in the context of healthcare is widely advocated and has been thought of as an initial step to becoming more aware about the clinicians' position in relation to patients and other key stakeholders (Kayes et al., 2015).

Clinicians who brought relevant aspects of their whole selves into the clinical relationships were experienced as humanising. Drawing on the metaphors used by Austin et al. (2006) and Drury and Munro (2008), these relational clinicians appeared to be operating in a *territory*, or a shared space where they are a sort of host, building *manaakitanga* to enhance the *mana* of the patient. They do so in part by bringing more of themselves, while remaining vigilant and aware of their own motives, attitudes and actions. This was the case irrespective of the technical content of their therapeutic approach. Furthermore, as with Austin et al.'s (2006) case study of Betty, described above (see Section 8.3.2.1), the findings suggest that clinicians may want to consider how sharing some personal information may be appropriate in some contexts, as patients experience this careful sharing as allowing them to see things in a new light, and possibly as a signal that the agency of their personhood is respected. This may contribute to patients becoming ready to enter into the therapeutic encounter and more willing to engage with it (as was the case for Betty in Austin's study, and Colleen in this study).

The experience of being listened to was the second component explored in depth with respect to the process of co-constructing readiness. Within this study, there are detailed descriptions of the listening behaviours valued by patients and accounts of how these behaviours were enacted. The findings demonstrate that it is possible for these listening practices to be achieved within the bounds of a traditional consultation time of a hospital setting. In fact, as with other research where clinicians mindfully and deliberately incorporated listening into their practice (Bright et al., 2012), time did not emerge as a constraint or a barrier in the current research. Other studies have also found that it is possible to create the space for people to articulate their reality within the usual time constraints of clinical interactions (Ellis-Hill et al., 2008). The themes identified and descriptions given in this study offer ways of practice that could facilitate this.

Although my intent was not to provide "tick-the-box" prescriptions for practice, I have attempted to develop questions aimed at facilitating self-reflection for clinicians. These questions are grounded in the findings and are based on what participants articulated with respect to their experience of being listened to. These questions are presented in Table 4 below. The purpose of these questions is to facilitate a values shift in how clinicians view the practice of listening as part of their practice.

Table 4

Listening Practice Questions for Clinical Self-reflection

Sub-theme	Description	Questions for self-reflection
The art of listening	Listening practice that contributes to the person feeling the clinician has a <i>listening mindset</i> : The physical gestures and mannerisms that invite persons to speak and feel assured they are listened to.	<ul style="list-style-type: none"> • Am I being deliberate about what questions I ask? • Am I asking too many questions? • Am I allowing time for patients to complete their answer, and giving them space to communicate fully before launching into the next question? • Am I spending most of the time facing the person and maintaining eye contact? • Am I excessively looking at my screen? • Am I approaching the person as “another human being”?
The act of listening	Listening practice that contributes to the person feeling the clinician is <i>engaging</i> with them: Active listening practices valued by participants.	<ul style="list-style-type: none"> • Can I relate other relevant information that may be of interest to the patient in the context of their symptoms? • Do I ask thoughtful follow-up and individualised questions? • Can I reflect back what I am hearing and check my understanding of what the person is trying to convey? • Am I showing interest in, and curiosity about, this person?
The heart of listening	Listening practice that contributes to the person feeling <i>heard</i> : Providing the space for the person to tell the story they want the clinician to listen to.	<ul style="list-style-type: none"> • Am I giving this person the space to convey what they want to communicate without pushing and rushing them? • Do I follow their “flow” whether it is focusing on physical symptoms or biographical information? • Do I ask questions about their narrative or mine? • Do I prematurely re-direct the person to focus on my area of interest? • Do they feel as if I attempt to take their every point into consideration? • Do I dismiss concerns out-of-hand? Do I ridicule, joke, or belittle the person’s thoughts and reflections?

The majority of current literature focuses on the professional’s perception of listening, with little emphasis on the perspective of the patient (Kagan, 2008b). Many of the approaches in teaching medical professionals how to listen focus on techniques and routines (Davis, Foley, et al., 2008; Shipley, 2010). This primary focus on techniques and routines may risk conceptualising a transactional, tick-the-box approach, versus a more values-based approach or a philosophy of practice that becomes more integrated into everything clinicians do. This study offers a simple and yet nuanced articulation of listening practices valued by patients. The listening practices were enacted across all clinical contexts, with subtle yet powerful variations.

Within the sub-themes constructed to explore what it meant for participants to feel listened to, this research offers a way of conceptualising listening that makes explicit the different components of listening practices that patients experience. *The art of listening* speaks to the simple, everyday gestures observed and judged by patients as indicating the absence or presence of a *listening mindset*. For example, clinicians who look at their notes and do not meet patients' eyes are experienced as not listening, whereas those who face their patients squarely, do not look at screens or at notes, are experienced as listening. *The act of listening* speaks to the *active, dynamic* nature of listening, which was highly valued by participants. It offers illustrations of how this was done, through questioning, reflecting, and storytelling. All these practices were interpreted by participants as indicating that clinicians truly listened and were able to offer something of their own to help participants expand their own thinking and ways of knowing. *The heart of listening* illuminates a more subtle aspect of the listening experience; the experience of being given the space to convey the story the participants wanted to convey about their illness. This was powerfully experienced as non-judgemental and, I suggest, as a way of signalling that clinicians *saw* their personhood. Together with the experience of something *observed and acknowledged* without feeling forced to get better, these expressions of listening were experienced as enabling and therapeutic.

A focus on how listening is both enacted by clinicians and experienced by patients could contribute to strengthening the ability of clinicians to empathise with their patients. The concept of empathy has been widely studied and its absence has been reported to be associated with patients' dissatisfaction and consequently there has been a growing movement towards teaching empathy in medical schools (Davis, Foley, et al., 2008). Interestingly, patients in the present research did not mention empathy as a discrete quality or competence they had experienced or perceived as important. Rather, participants' focus on being *seen* suggests that, from the perspective of the patient, the experience of empathy might be primarily concerned with the experience of mutuality and being listened to.

8.4.3 Practice implications for the transformative educational experience of the WPTA

The non-dualistic ontological assumptions regarding illness aetiology and progression held by WPTA clinicians appeared to orient them towards focusing on, and perhaps even prioritising, the therapeutic connections with their patients which are then

experienced as therapeutic in-and-of-themselves. It is important to note these humanistic practices are not unique to WPTA, and indeed support Kayes et al. (2015) and Kayes and McPherson (2012) assertion that the therapeutic connection established between clinician and patient may be a core component of practice, and could be considered a therapeutic intervention in its own right. However, it appeared from participants' accounts of their prior care experiences that they were more commonly experienced in WPTA than in routine care.

Advocating for clinicians to reflect on their own beliefs and attitudes towards the people they treat, because these shape how they treat, is increasingly advocated (Nijs, Roussel, Paul van Wilgen, Koke, & Smeets, 2013). Therefore, prompting trainee clinicians to consider the extent to which they hold implicit dualistic assumptions about illness aetiology as part of clinical education, may contribute to healthcare graduates becoming more open to self-reflection about the extent to which these impact on their ways of being with their patients.

It has been established that the beliefs and attitudes of physical therapists towards musculoskeletal pain influence the recommendations they provide to their patients (Domenech, Sanchez-Zuriaga, Segura-Orti, Espejo-Tort, & Lison, 2011), and that these also influence the beliefs and attitudes of their patients towards their own pain and how it should be managed (Nijs et al., 2013). In a randomised controlled trial, Domenech et al. (2011) demonstrated how biomedical training shapes the therapists' attitudes and core beliefs towards musculoskeletal pain and subsequent treatment recommendations. Clinical practice guidelines for clinicians encourage physical activity in the absence of severe medical pathology or neurological impairment, this being taught as part of the curriculum to all students in their study. Domenech et al. (2011) found that students who received a brief training module on the biopsychosocial model of back pain management displayed improvement in beliefs and attitudes and were significantly more likely to prescribe recommendations in line with these clinical practice guidelines. The control group, who instead received lectures focused on the biomechanics of the spine, were unexpectedly found to have reduced recommending activity levels compared with what they were taught.

It would be inconsistent with the humanising and one-to-one relationship values of the WPTA to provide a cookbook-instructions style of recommendations for clinicians as a consequence of this research. In fact, the participants in the present study themselves recognised that a checklist or prescriptive guide to behaviours would be inconsistent

with the WPTA framework. This is illustrated in the following quote from a participant who reflected on what other clinicians can learn from her WPTA clinician:

It is challenging, because there is no formula here, and it takes more skill and experience to do this. That's why it is harder, because you can't. You know, it's like the difference between someone who is paint-by-numbers and an artist. It's a combination of those skills. So that's challenging.

The findings also offer an insight into what might contribute to forming authentic and transformational relational experiences. One implication for practice (and education of practitioners) is that overly focusing on the centrality of the *story* in WPTA, without attending to the emotional impact on the person being treated from the connection being made for them, can be experienced negatively, as was the case for Jason (see Chapter 6, Section 6.6). The findings suggest that in training clinicians to work in the WPTA, emphasis should be given to the ways by which the therapeutic relationship is established. Training should also highlight the powerful experience from the perspective of the person being treated when WPTA clinicians provide them with the space to draw on, or form their own understanding through this nuanced practice, rather than being told about the links.

Finally, the choice of metaphors used by participants (such as “a key to unlock a door”, “connecting the dots” and “open doors into understanding” – see Chapter 6, Section 6.7) to articulate what WPTA meant for them, suggests that they have experienced the approach as inviting them to draw on potentially latent inklings they may have had about the links. It appears that participants experienced WPTA as activating and empowering them to draw on their own resources without feeling judged.

The WPTA appeared to have successfully activated participants' resources and strengths, and this appeared to help them feel better able to take charge of their own condition as experts and “peers in a way” because they were able to move “toward” and “with” the therapeutic experience (Drury & Munro, 2008). This finding provides a patient view that aligns with Bright et al. (2012), where the clinical researchers found that when focusing on practising in a client-centred way and on their listening practice, they had to change their conceptualisation of their professional identity from one that saw themselves as expert clinicians with all the answers to becoming more like coaches “handing back power to the client” (Bright et al., 2012, p. 1001).

8.5 Implications for further research

There are a number of implications for future research which emerge from this doctoral work, and these are outlined in this section. The first is concerned with extending the focus from the individual patient as the only active agent in their experience of chronic illness, to exploring the role that relationships with healthcare providers play in that adaptation. One proposed way of doing so is by using the expanded conceptualisation of chronic illness as a biographical disruption. The second concerns the potential for a range of data collection techniques emerging from this research to develop deeper insights. The third is concerned with the potential for future research to further explore the extent to which clinicians' implicit dualistic assumptions may impact on patients' experience. The fourth is concerned with researching the experience of clinicians who transition to practise WPTA and work to incorporate these humanistic dimensions into their practice. Finally, the fourth is concerned with attempting to better quantify the therapeutic impact of the WPTA.

8.5.1 Extending research focus from the individual patient

This doctoral study highlighted that research into the experience of the person with a chronic illness without attending to or including the impact of the care, and experience with the health system, has the potential to miss an important aspect of patients' lived experiences. Therefore, I would suggest that any study concerned with patients' experiences with chronic illness, treatment approaches and regimes ought to provide some space for patients' reflection on the care experiences they have received.

Qualitative studies in which the sole focus is on the personal experience and personal resources of the chronic patient are relatively common—see, for example, Griffiths et al. (2014). However, focusing on personal experience, response and adaptation to chronic illness, without attending to the influence of the medical system on that experience, may limit the findings and potentially be problematic if clinical recommendations are then made. This is because the exclusive focus on the patients themselves suggests that researchers fail to consider the impact of relationships with medical professionals, and their experiences within the “system” on the ways people who live with chronic conditions care for themselves, and are able (or not) to adapt and live a full and fulfilling life. Therefore, such research may result in findings solely focused on psychological adaptation and personal response to illness.

These types of findings may give the impression that successful navigation of the chronic illness care experience rests with the patients themselves. For example, May et al. (2009) described how the authors of a relatively recent meta-ethnographic synthesis on studies of patients' experiences of chronic illness reported that patients made active decisions not to comply with the biomedical treatment prescribed to them. May et al. (2009) highlighted how the researchers did not consider that such decisions may result from the unreasonable burden of the treatment, nor did they account for the impact of the care relationships on these decisions. As a consequence, the findings from this type of research appear to imply that the patients' decisions were only to do with patients' personalities or resources, independent of the quality or complexity of care they received (see, for example, Röing and Sanner (2015)).

The expanded reconceptualisation of chronic illness as a biographical disruption, proposed in this research, could be used as a sensitising concept in future research on the experience of people with chronic illness. It may be the case that persons with chronic illness suffer less of a disruption when they experience supportive, mutual relationships with their primary care providers and that they may be more likely to follow the advice given to them. It could also be the case that when these relationships are established, the clinician is more likely to be attuned to the treatment burden the patient is enduring, and adjust and simplify it accordingly. Therefore, such research may have the capacity to further highlight the role clinicians play in activating patients' abilities to successfully adapt to living with chronic conditions and possibly become asymptomatic.

8.5.2 Data collection methods and techniques for deeper insights

The present research highlighted the value of having a range of data collection tools to elicit more in-depth insight into the experience of a particular phenomenon. For example, the use of the timelining technique provided the space first for myself, and then for participants, to elucidate aspects of the care experience that had the most impact for them, both positively and negatively. Drawing on this approach helped participants to articulate in more depth what it was that they perceived to be unique to the WPTA. As a consequence, I was able to develop insights into their need for their difficult care experiences to be recognised by clinicians who seek to establish emotionally intimate therapeutic relationships, such as in the WPTA. Arguably, if I had concentrated solely on their experiences with the WPTA clinicians without providing the space for broader reflection, this important insight would not have been possible.

However, it is possible that I have uncovered their care experiences as particularly influential because of my focus of inquiry and personal experience of illness and treatment. Arguably, there may be other equally important aspects of participants' social worlds which influenced their experiences (such as their spouses, workplace, extended family, friends, etc.). Therefore, future research could explore how other important personal relationships in patients' lives interact with, and impact on, their care experiences.

Finally, central to the findings of this research was the exploration of the listening practices of WPTA clinicians. These were explored vis-à-vis participants' accounts and descriptions. Utilising a broader range of data collection methods, future research could further explore the complex practice of deep listening by WPTA clinicians and others by combining interviews as well as observations and video recording of clinicians in practice.

8.5.3 Further exploration of the impact of clinicians' implicit assumptions about health on patients' care experiences

Another aspect which comes to light from this research is the relevance and importance of exploring clinicians' implicit assumptions about disease aetiology, in relation to patients' care experiences. With very few exceptions, most of the studies reviewed for this doctoral research did not examine these beliefs. Given that it is acknowledged that clinicians' own beliefs and cognitive schemas affect the way they practice (Kayes & McPherson, 2012), it is suggested that including an explicit consideration of clinicians' ontological assumptions could enhance the insights generated from qualitative research endeavours concerned with patients' care experiences.

Although implicit in the findings, this research made no attempt to explicitly explore the explanatory mechanisms patients may have had about how the WPTA impacted on their experiences with their conditions. Future research could explore the explanations patients may have had regarding how they clinically benefited from the WPTA, or did not. Similarly, it would be useful to explore clinicians' perspectives. Indeed, future research could further explore any hypothesised explanatory mechanisms which have arisen from this research (e.g., therapeutic relationship, non-dualistic assumptions) and existing theoretical writings (e.g., metaphor and story) (Broom, 2007). This would serve to advance our understandings of the underlying mechanisms which contributed to the documented clinical success of the WPTA in hard-to-treat or resistant chronic conditions (Broom, 2010; Lindsay et al., 2015).

8.5.4 Researching the experience of WPTA clinicians

In their edited book, Broom and Joyce (2013) brought together stories of clinicians, from diverse clinical backgrounds (medicine, physiotherapy, psychotherapy, dieticians etc.), who transitioned to practising WPTA in their clinical context. In these accounts, the clinicians disclosed the profound impact practising in this way had for them. These accounts bring to light the positive dimensions for some, such as finding ways to incorporate more of themselves into their practice, and the challenging aspects for others, such as trying to practise in this way within an unsupportive and even suspicious biomedical organisational context (Broom & Joyce, 2013).

Future qualitative research could specifically attend to the experiences of WPTA clinicians. Such research could explore, in depth, the personal consequences for clinicians who practise in this way. Such research could attend to the personal impact of working to incorporate these profoundly humanising dimensions as part of routine care. It may be the case that clinicians find it challenging and draining, or they may (as in Broom & Joyce, 2013) find it liberating, transformative and providing them with a way to re-engage with their profession. In either case, such research could help provide important insights that could guide the training of WPTA specifically and other clinicians more broadly on how to sustainably incorporate these humanistic dimensions into their practice.

8.5.5 Better quantifying the therapeutic impact of WPTA

Within this study, there was no attempt to quantify the therapeutic impact of the WPTA. Nor was there an attempt to explore the economic benefits of this approach when it comes to the possible reduction of service use and hospitalisation by patients with chronic conditions. Although Lindsay et al. (2015) demonstrated that WPTA had resulted in long term resolution of chronic urticaria with a small group of patients, and their subsequent cessation of hospitalisation, further research could explore the efficacy of this approach compared with mainstream approaches.

Furthermore, making WPTA more broadly available could be seen to be costly, as longer appointments may be needed. To help support policy decisions regarding making this approach more widely available, future research could explore whether experiencing WPTA leads to reduction in use of health services by patients. Such research would enable balancing the financial impact of extending appointment times to

enable WPTA to take place, with the possible savings resulting from reduction of overall service use by patients over a longer time frame.

8.6 Summary and conclusion

Within this chapter, I discussed the three novel contributions this doctoral study offers: expanding the concept of chronic illness as a biographical disruption and enhancing its therapeutic relevance, reconceptualising readiness as co-constructed, and illuminating the profoundly humanising and transformative educational experience of WPTA. I elaborated how these contributions challenged and advanced current knowledge of WPTA and the treatment of people with chronic conditions more generally. Key methodological considerations were highlighted and the limitations and strengths of the design were outlined and discussed. Practice implications for each of the contributions were explored in some detail, and the implications for future research were offered. Following this summary and conclusions, I offer a postscript documenting my personal understandings following the doctoral journey.

This research captured the essence of participants' experience of "*being seen rather than being looked at*", which appears to be a critical component of care. At its core, it is experienced as a humanising acknowledgement for one's personhood within a therapeutic encounter. Through explicating the subtle and profound ways clinicians achieved this, this research makes significant contributions to knowledge with respect to the ways clinicians can co-construct patients' readiness to enter into any type of therapeutic relationship. Further, this research is the first to demonstrate the profoundly humanising and transformative educational experience of WPTA from the perspective of the person being treated. This has implications for clinical practice, and clinicians' education. The findings of this doctoral research can serve as a base for shifting research focus from the individual patient as the sole active agent in their experience of chronic illness to exploring the role relationships with care providers play in this adaptation. This research also demonstrated the insights that can be gained on the care experience of patients, from explicitly attending to the impact of clinicians' implicit ontological assumptions about the nature of health and illness.

8.7 Postscript

I deliberately decided to include this section after the summary and conclusions, so that it book-ended the doctoral journey. I felt that given the first chapter focused on my personal experiences and assumptions going into this process, some readers may

wonder what I personally thought coming out of the process. Looking back, my pre-assumptions were concerned with the individual's orientation, namely readiness. I only had a surface understanding of the importance of the relational dimensions. The *what* of WPTA was what I was most interested in – the content of the therapeutic approach and its uncovering of meaningful relationships between life history and events and illness. Looking back, I now understand the extent to which I had taken for granted the relational aspects of my own therapeutic experience which made it possible for me to benefit from the profoundly humanising and transformational *educational experience*, and indeed *reconceptualise* my own personhood. The intellectually exciting aspect of the content captured my attention, whereas I was almost completely unaware of the magnitude of the tacit and powerful aspects of the therapeutic relationship that made it possible for me to comprehend those. I certainly did not reflect about what aspects of the relationship made it possible for me, other than a vague notion of safety.

What I have come to comprehend through this research is the capacity of qualitative research to “*delve beneath the surface to explore issues that are assumed, implicit, and have become part of participants' common sense*” (Tracy, 2010, p. 843). I have come to see that the taken-for-granted practices of WPTA clinicians, or the *how* of their practice, is the thing itself. I now comprehend how the therapeutically beneficial aspects of WPTA, and any other encounter between two people where one's role is to enable the other to get better, are dependent on the capacity of the *healer* to *see* the person they are trying to heal. The technical knowledge of course must be there, but it is only the starting point. I came to conceive that this experience of *being seen* is the feeling that someone else is truly seeing the whole of you. Risking hyperbole, I argue that this is a profoundly existential experience, as mostly we spend our lives with people who only *look at* aspects of us. Who look at our professional background, or at our symptoms, or look at our childhood trauma. From *apprehending* that the experience of *being seen* is somehow important, I now *comprehend* that it is an existentially humanising and healing experience that unfortunately too few people experience.

My doctoral research has confirmed to me that being introduced to non-dualistic concepts as they pertain to health and wellness in the context of this relationship can be transformative, in that patients come to reconceptualise their identity with respect to their illness so that they, like me, can experience freedom and hope. However, I now grasp that to introduce radical new ways of thinking about one's self is something that should be treated with utmost care and reverence. Introducing such notions may

destabilise the very core of one's personhood. Now I see that anyone who is involved in activities that are concerned with changing the way another person thinks and behaves, has to *earn* the right to do so. And the ways by which we *earn* that right is through being careful and mindful of our words, our actions and our capacity to recognise the personhood of another, and of being experienced as doing so. In a sentence, my conclusion at the end of my doctoral journey, is that it is through the *how*, not the *what* where profound experiences and changes occur.

While undertaking this PhD, my son was studying for his Bar-Mitzvah, the Jewish coming-of-age ceremony for boys aged 13. In one of his lessons, our Rabbi explained to me that much of Judaism is built on the concept of **נַעֲשֶׂה וְנִשְׁמָע** Naase Ve'Nishma, which literally translates to, "We will do and then we will hear". He explained to me that one of the ways this has been interpreted, is that the Israelites, when offered the Tora (the teaching of the Jewish god), agreed to do *what* was asked of them first, before they heard *why* it was asked. The Rabbi explained that being Jewish comes from the acts that constitute our religion, the act of celebrating the Shabbat, the holidays and, of course, the Bar-Mitzvah. That through *doing*, we come to *believe* or *see*.

In concluding this doctoral thesis, I do think that making explicit the ontological dualistic assumptions underpinning much of the teaching of modern medicine is important. However, I now think that we need to consider shifting the almost exclusive focus on content or the *what* of clinical sciences, to include, as equal, the *how*, the ways of acting and being. My reflection in concluding this thesis is that clinicians who work to embody these humanising practices, are likely through doing and experiencing, to shift their own preconceptions about the dualistic nature of health and illness.

(Postscript written on 3rd November 2017.)

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Appendices

Appendix A: Consultation summary

Rationale:

To interview a range of WPTA clinicians who work in a variety of settings for the purpose of understanding how the approach works in different settings pragmatically speaking, as well as:

- Enabling the research to be conducted in an ethical and respectful manner
- Helping me to explicitly account for my own perspective as a patient so it is transparent in the findings
- Thinking through how power imbalances are accounted for
- Facilitating the process for purposeful recruitment
- Thinking through ways to obtain the richest possible findings

Areas explored:

- What would clinicians that are already operating from the WPTA be interested in finding out?
- Whether or not to use focus groups rather than one-on-one interviews
- The extent to which a semi-structured interview is appropriate
- Exploring different wording of possible questions
- Places to interview, usage of audio and video
- The use of the timelining tool
- Whether a support person is required for the interviewer/participants

Clinicians interviewed:

Three medically trained WPTA clinicians and two WPTA psychotherapists were interviewed during the consultation phase. The key insights, which shaped the design of the study obtained from this phase, were:

Clinicians are interested in finding out:

- What do patients experience when they encounter someone who listens to them as persons? Believe it can be positive but also uncomfortable so therefore what goes through their minds?
- What makes people come back and not come back?
- To what extent meaning or relationships with clinician play a part in the patients' own sense making of the process
- Reconciling the time needed for the WPTA and resources available

The consultation impact on the research design:

1. Focus groups were seen as inappropriate for this study by all the clinicians and all felt that using semi-structured interview questions which evolve with the research was the best approach.
2. People who see psychotherapists seek to see them for what they (the patients) define as mental health issues. Chronic physical symptoms are secondary. This

led to the decisions to start with the immunology department as the pathway to referral was through a chronic condition.

3. Use devices that elicit deep and open responses. This led to the use of the timelining technique at the beginning of the interviews.
4. Psychotherapists who are aligned with the department also see many people who are seen in the immunology department. Therefore, when interviewing them, I am likely to hear about these experiences as well. Furthermore, some clinicians commented that people with some conditions like immunology ones, seem to respond faster to the WPTA, whereas people with conditions that involve chronic pain seem to be slower. These two insights subsequently helped inform the decision to interview people who are seen by WPTA physiotherapists after completing the interviews in the immunology department.
5. Interview people with a range of chronic conditions, not specific conditions, and include people who have a concrete diagnosis and those who do not, as well as immunological conditions and chronic pain.
6. Recruiting will best be carried out through the clinicians.
7. The best way to account for my position/bias as a former patient is by being as explicit as possible.

Appendix B: Detailed methodological considerations table

Type of methodology	Link to epistemology and tradition	Brief description of my understanding	Appropriate questions to ask in the whole person context	Sampling implications	Data collection implications	Degree of theoretically imposed structure on the analysis or methodology
Pluralistic orientation towards qualitative methodology (Chamberlain et al., 2011). Specifically, thematic analysis (Braun & Clarke, 2006).	Pluralistic orientation and thematic analysis within it are fairly 'agnostic'. They can be conducted with both realist/essentialist and constructionist paradigms. (Braun & Clarke, 2006)	Suited for very 'high level' explorative questions because of its agnostic nature which I see as very inductive – it allows for the research instruments to evolve throughout the research process in a responsive manner to the analysis.	What themes emerge when patients are asked about how they changed or benefited and what they gained from the whole person experience? What are their theories of what happened to them? What are the assumptions patients hold about their experience that underpin the theme? What are the implications of the themes for practitioners? What conditions have given rise to the 'gaining' themes?	Thematic analysis is silent on research design elements such as sampling implications and therefore is arguably a method, not a methodology. But writers such as (Creswell, 2007), argue that the design of qualitative research is emergent and that the initial plan cannot be overly tightly prescribed as the phases of the process may shift and be modified.	A range of data sources is possible including semi-structured interviews that can be adapted throughout the research as the analysis begins from the first transcription (Braun & Clarke, 2006). Also, other kinds of relevant data including the web, existing videos, existing writing and documents relevant to the topic at hand which could mean that I could use the existing videos of patients' interviews, video recording of Brian talking about the approach, and possibly the latest book of practitioners' accounts as data for the analysis.	Low – the structure is generated by the researcher in dialogue with the research question – but the level of rigour is paramount, by following a transparent approach to coding and documenting the coding decisions. There are plenty of academic publications here to draw on (Braun & Clarke, 2006).

Type of methodology	Link to epistemology and tradition	Brief description of my understanding	Appropriate questions to ask in the whole person context	Sampling implications	Data collection implications	Degree of theoretically imposed structure on the analysis or methodology
Phenomenology (Crotty, 1998)	Social constructivism (Creswell, 2007) Constructionism (Crotty, 1998)	When a researcher seeks to understand the lived experience about a phenomenon. Suited for finding out the universal (?) essence of all persons about a particular phenomenon (Creswell et al., 2007). Or in other words, phenomenologists seek to produce a universal essence of the individual's experience with a phenomenon (Creswell, 2007).	I would collect data about the phenomena of whole person therapy from those who have experienced it and develop a composite description of the essence of that experience for all of the patients which will consist of what they experienced and how they experienced it. I would need to ask specific questions such as: <ul style="list-style-type: none"> • What does the timing of the introduction of the approach mean for patients with chronic conditions? • What is the meaning of 'love' in the context of the whole person experience? 	Several individuals who have a shared experience. Accounts recommend between 5–25 (Creswell et al., 2007)	Primarily interviews, can use documents, observations and art. Could use drama and films as well or novels that account for the experience. The analysis strategies include bracketing, statements, meaning units or themes, textual description to 'uncover' the essence of the phenomenon. (Creswell et al., 2007).	High and qualitative methodologies specialists e.g., (Creswell et al., 2007) advocate that the researcher links back extensively to the philosophical underpinning of this approach. "Across all these perspectives, however, the philosophical assumptions rest on studying people's experiences as they are lived every day, viewing these experiences as conscious, and arriving at a description of the essence of these experiences, not explanations or analyses" (Creswell, 2007, p. 253).

Type of methodology	Link to epistemology and tradition	Brief description of my understanding	Appropriate questions to ask in the whole person context	Sampling implications	Data collection implications	Degree of theoretically imposed structure on the analysis or methodology
Narrative research	Social constructivist perspective (Willig & Stainton-Rogers, 2013) Post-modern (Crotty, 1998).	When detailed chronological stories can help understand the problem. Suited to chronological/story oriented questions – about a small group of individuals and how they unfold over time (Creswell et al., 2007).	What stories do select patients who might represent a ‘successful’ and perhaps ‘unsuccessful’ whole person experience tell us about their illness and the whole person process?	A small group. Creswell et al. (2007) recommends one or two individuals because of the extensive work involved in the rewriting of the stories. For a PhD project I could do more but not many more. The focus is very much about the individual.	Data is gathered through collecting participants’ stories by asking them to tell their story in a very unstructured way. From others’ reporting on the individual experiences, relevant documents such as letters and journal entries (Creswell et al., 2007).	The analysis is referred to as restorying which consists of analysing the stories of a few individuals for key elements (e.g., time, place, plot, and scene) and rewriting them in a chronological sequence. There are quite systematic and ‘prescribed’ approaches to this (e.g., Willig & Stainton-Rogers, 2013). Including the focus on what is being retold (the fabula) and how it is retold (the syuzhet) “Narrative research analysis, with its chronological restorying and story focus, relies on other analytic procedures” (Creswell, 2007, p. 245).
Case study	Pragmatist? Could be constructivist in some contexts. Very prevalent in psychology/psychotherapy and law. I wasn’t able to pinpoint it to an epistemology as such because of its use across many disciplines.	When the researcher can access a case bounded by time or place that can help inform a problem. Suited for gaining an in-depth understanding about how different cases provide insight into an issue (Creswell et al., 2007).	What did a select number of patients who suffer from ‘biomedical’ chronic conditions gain (or not) from their experience of the whole person therapeutic process when working with psychotherapists.	An event or programme or more than one individual. Could be a case study of patients who didn’t find the whole person effective – or a case study of patients who had ‘diagnosable’ chronic condition or could be patients with a ‘somatic’ chronic condition.	Multiple forms of data are used including interviews, observations, documents, and artefacts. Interviews are likely to include in-depth descriptive questions (Creswell et al., 2007). Might require me to work also with the therapists to ensure I have a thoroughly contextual idea of the patients’ circumstances.	Risk of methodology seems low. The focus is on description of the case/s, the themes and cross cases themes. “Case study research builds an in depth contextual understanding of the case, relying on multiple data sources.” (Creswell, 2007, p. 25)

Type of methodology	Link to epistemology and tradition	Brief description of my understanding	Appropriate questions to ask in the whole person context	Sampling implications	Data collection implications	Degree of theoretically imposed structure on the analysis or methodology
ID (Thorne et al., 1997)	It is grounded in an interpretive orientation that acknowledges the constructed and contextual nature of much of the health illness experience, yet also allows for shared realities.	Designed for the explicit purpose of understanding people's unique experiences as well as shared experiences. Also very connected to the practical nature of nurse researching and that they have never assumed their science to be only theoretical.	<p>'Being seen as a whole'.</p> <p>A description and interpretation of the experiences of undergoing the whole person approach to treating chronic illness by medically oriented practitioners from the perspective of those who have been treated.</p> <p>This type of inquiry will be respectful about the aggregate experience in a manner that will not render the individual experience invisible.</p>	Adopts a grounded theory inspired theoretical sampling to ensure maximum variability from predictable various within the theme studied. This approach does caution about making claims based on small samples of each variation.	Because of the risk of having people with very unique experiences that might not allow a greater generalisation, they recommend using many data points. The approach advocates the judicious use of a range of data sources including interviews but also advocates going beyond into lay print and other media information as they see this as important for the generation of practical knowledge. Advocates the use of secondary analysis.	It seems to be low for me because of the very applied nature of this research. Low risk of methodolatry as every decision needs to be justified in relation to the phenomenon of interest and the target audience.

Appendix C: Summary of pre-pilot interview

Interview questions used in the pre-pilot

- (For charting the illness progression and for identifying the transition point to WPTA) When were you first diagnosed? How long did you have the symptoms beforehand? Tell me about your initial treatment? What made you consult with a WPTA/whole person practitioner?
- What strategies did you use to get well before WPTA?
- How do you feel now? Any symptoms? How often do you get checked? Is the illness impacting on how you live your life? If so how?
- Tell me about the initial consultation with the WPTA practitioner? What did it feel like? What did you think about it? What made you want to continue working with her/him? How did it feel to you when you found a practitioner who seemed to understand you as well as your illness?
- Looking back, can you describe to me in your own words what the WPTA experience felt like to you? (use prompt as required)
- How was working with the WPTA practitioner different from your biomedical (doctor) lead to that date?
- What do you feel changed in you as a result? Thoughts? Feelings? Relationships? Body? Benefits? Gains?
- Would you recommend it to other people who are experiencing chronic illness? Who would you recommend it to? Why? Why not?

My reflections on the pre-pilot following initial listening to the recorded interview:

Summary comments:

I think that conducting the interview as a pre-pilot was an excellent thing to do – it highlighted several key things to me, that the interview should be conceptualised in two parts – the pre-treatment part: symptoms, diagnosis and biomedical and other treatment, best accessed through using the timelining technique. The WPTA part will require the use of a metaphorical device, I am really drawn to getting them to bring an object and exploring via the object. Taking a photo of the object and then including that as part of my PhD. I feel that if I brought an object the result would have been much deeper and closest to the essence of the experience as a whole.

Also listening to it highlighted to me the importance of asking lots of follow up exploratory questions to clarify – will need to ask permission to go back and ask for clarification and will ask if they'd like to be involved in the validating stage – asking about the themes and if those make sense.

I am also still very keen to suggest to them that if they'd like they could write a letter to their WPTA practitioner about their own reflections following the interview and send it to me to include in my analysis. They could of course also choose to send it to the practitioner. I find writing exercises very powerful for myself, when I was sick especially, and for my own coaching clients.

‘Sample raw notes’:

The first section about symptoms is very meaningful. Needs flushing out. Question should start with tell me about your symptoms. Keep it broad and explore symptoms BEFORE talking about diagnosis.

Timelining very effective too. I can give them a pen and me a pen and the A2 paper between us so we can both draw on it. Gradually I should draw less and let them ‘take-over’ to draw what comes to their minds.

Also, I realised it is very important to find the trigger for what made patients see the MB practitioner. I noted this verbally during the interview but also on second hearing before I heard me say to that it is really important to find out when, why and what exactly made patients want to see BD practitioner. Important questions around when they went to MB practitioner and what made them/promoted them to do so (I note that in context in the hospital this would be less relevant, but I do think it is still really worth asking).

Something about listening. As I listen to me being interviewed it strikes me that there is always a risk that your own professional background would programme you to listen to only certain things. Good MB practitioner listen to EVERYTHING. Brian’s listening work.

Use the timeline to be clear when the patient saw MB. In relation to symptoms diagnosis and treatment.

Couldn’t answer what did MB feel like for me. Need to bring an object and use that to explore feelings (finding literature on this now). I say in my interview that the ‘feel like’ question has to be a metaphorically based or an object question. Because words in themselves feel inadequate as I myself am being interviewed. Need to research metaphor-based interview techniques! (finding literature on this now!).

Need to chunk the interview into two key parts. Timelining for symptoms, diagnosis and introduction of MB being the first part. The second part should revolve around the object for the mind body experience itself. With clarifications questions at the end.

Listening to the interview with me made it very clear that I still have quite the bias against psychotherapists and psychologists as I myself wouldn’t recommend ‘just’ a psychotherapist to someone with ‘real’ somatic issue – the question is a good one, but also what do I do about my own bias?

Appendix D: Extract from original positionality interview in May, 2014

LS asks: What will my findings show in the thesis.

“I think that one of the findings that will be really strong for people will be the importance of being respected as a whole person. After being marginalised and compartmentalised by the medical profession to arrive with someone who is part of the mainstream, not alternative medicine, herbalist, etc., but actually part of the mainstream who treats you as a whole person, I think that will be echoed everywhere I go. That sense of (big sigh) I can just breath, this person sees (emphasised) me as a whole. I think that would be across no matter how articulate people are.”

“I just get somatic metaphors, I am a very physical person. I think Brian’s worried I’ll be disappointed that others don’t see them. But I have no doubt that others won’t. I am a coach, I work with lots of people, I do know what people are like. But I do think that everyone will be able to articulate in one way or another, that sense of (big sigh) this person sees me as a whole, which then, this sense of respect and calm, which enables you to go to places you weren’t able to go to before, because you weren’t seen as a whole.”

Appendix E: Extract from second positionality interview in August, 2015

LG asks me what made sense about Sally Thorne's presentation about ID?

The whole, and I have to be careful that I am not coming across as an acolyte and I have been warned as well. It made sense because of her orientation. And her orientation comes from practice. She is a nurse, qualitative researcher; she grounds herself in the practice. Not the philosophy, the practice. And one of the things that resonates with me the most, and that is part of my own ethical epistemology is that she says all health research should be done as if it will be applied by someone tomorrow. And that is something that resonates very strongly with me because I think that is a responsibility to think about what you are writing as if it will be applied tomorrow.

I see in my work to date how things are thoughtlessly applied from research to practice. So to give you an example, I was called from a major law firm to calm their senior associates down because they measured their Emotional Quotient (EQ) and they didn't do very well... It was measured by a commercial company that took the research on EQ and developed from a personality test called the Hogan's, they developed a measure of EQ which is beyond ridiculous and yet it is done. Done with very intelligent people and creates damage. I have had to pick up the pieces so many times when things were applied from research on populations thoughtlessly on individuals.

Appendix F: Example of a free-flowing memo written while listening or watching the secondary data

There was a lot 'being held' that
came through about her experience,
the descriptions of delirium as she
didn't 'hit the box' and very powerful
certainly further illuminates the context
the constraining picture of clinician
as educator. She refers to the
reality of living with chronic illness
the impact on life & that most
people are open to be educated to
help them live better. The clinician
who educates the person vs that
who elicits the illness. Also
strong quotes that speak to the
professional unit & element

Appendix G: Example of a memo written during the secondary analysis process

March 2016

“Most of the women in the videos reach a tipping point when they tried so many things and were frustrated with their experience and that they still were experiencing all the symptoms and almost the referral to the MB clinician was a last resort and for a couple of them had no idea that he was more than a doctor and then discovering that he was more. And what allowed them to remain open was a combination of a sense of something bigger but also because he was a biomedical doctor that gave it a legitimate space and helped them get to that point – and then his sense of belief and faith in his process led them down the process.”

What happens for them once they are in that space?

Words they used, is naming the shame, door to an understanding, and all of them used a different language too.

And that they went in was to rid themselves of the physical disease and ended up letting go of something much bigger in their lives. In a sense that they felt something really deep. They had such trust in his faith in the process – and I highlighted that he has trust in them and their resources.

Julie wanting to hold on to difficult emotions.

The questions of what can be learned? All the interviews have the life experience that comes up – when you think of biomedical practitioner, they are unlikely to delve to the history in the same way – interesting to think about either is it the delving into the life history or is it something else by allowing the patient?”

Themes thoughts after doing 7/8 secondary analysis 22/2/2016

think comprehension dimension. 'sense making' → a door to understand → take responsibility → take control → take charge

① understanding the illness in the context of one's life

had a feeling it was related to my life

Voicing

being listened to

naming emotions

invoking anxiety

Facilitates wanting to try something new

anxiety of body a physical condition

Very important aspect coming through.

② person feels

Feeling that there are mental stress under the stress

Feeling

as a person

SAFE

Not alone

Secure

Scott + unknown not practical or physical

claiming why have you come to see me?

person centered experience

giving foods the hair test

Brassic like style changes

Food allergies a answer

medication a side effects

patients want this approach to be more realistic practical

Authentic therapeutic experience

confidence of therapist

skills

calm

listens

not by numbers

own narrative about illness

Feelingness

openness

not a sense about the connection

freedom to talk about what she wanted

How?

patients getting better

confidence

patient in charge

9/8 in re if themes confirmed from 7th interview

Appendix I: Candidate theme development following secondary analysis March, 2016

Overarching concept	Theme name	Definition	Illustrative quotes
Crossing the threshold. This concept refers to themes that relate to each other in that they speak to the person's mindset and readiness to enter the therapeutic relationship.	A sense of physical readiness: 'I've tried everything else' the ever present, unpredictable body.	Common to all interviews was a sense of people wanting to find a way to 'tame' their unpredictable symptoms and their impact on their lived lives. I continually noted that this is a very important aspect coming through of chronic illness and the experience of people of the symptoms which appear 'out of nowhere' almost like a boogie man which has huge impact on the ways they live their lives. I believe this aspect of chronic illness is under-articulated in the research that I've read. For all of the people interviewed, this was the catalyst into trying anything new that my help them. My interpretive judgement at this stage is that this is more important than the intellectual readiness aspect.	<p><i>"And not knowing why. It is the not knowing why, the not knowing when it is going to happen because it didn't. You never knew when it was going to happen because I didn't know what my triggers were as to what was causing it to come on and then of course it can, you know you get it on the Monday and I'm screwed for three days. There are times when I literally cannot come to work for three days because I can't get my shoes on and I can't walk."</i> (CSU research project, second patient after completing her sessions)</p> <p><i>"I said to my GP 'There's got to be something else, I am not going to have these treatments anymore, these heavy-duty ones.' And so he put me onto Brian."</i> (JL Video documentary interviews)</p> <p><i>"And sometimes the welts used to be a sort of a pre-warning to something else. Not always. It was really unpredictable, it was unpredictable."</i> (CSU research project 4th patient after completing therapy)</p>
	A sense of intellectual readiness: Sensing the connection	Some articulate without being prompted that they had a sense that their experienced lives, their mind, and their illness were all connected and therefore encountering a clinician who approached it all as connected 'made sense'. This theme is distinct from the 'door to understanding' theme because it is concerned with the patients' orientation towards the approach – being more open to it at the outset. It is important to flag as whether or not this readiness is important for engaging in the non-dualistic therapeutic process should be explored in the primary data gathering process.	<p><i>"I completely believe in all that sort of stuff. If you're a sour, mean person your body's not going to be good to you, nice to you, in return really is it. I truly believe there's a huge connection between your mind and your body in terms of how things manifest themselves."</i> (2nd patient CSU research project 1st interview after 2 therapeutic sessions)</p> <p><i>"And the things that he talked about were things that I had always believed like the connection between the mind and the body and how the body expresses what's going on in your feelings and the whole idea of integration."</i> (Lesely, video documentary interviews)</p> <p><i>"Well I think I probably recognised it all the way along. It just it was never verbalised or I probably just chose not to recognise it. I probably didn't understand it as well."</i> (CSU research project 4th patient after completing therapy)</p>

Overarching concept	Theme name	Definition	Illustrative quotes
Engaging in. From being ready to enter this new territory, what is it that draws the person into the therapeutic relationship?	Deep human connection	The experience of being one to one with a medically trained person who has deep experience and expertise, but is not 'bound' by their professional identity and still allow themselves to be there as another human engaging on a human level with the patient.	<p><i>"He just stopped and made me think. But it was just talk about the week and okay what did you think, how did you react? He didn't tell me to do anything he just made me sort of think really, stop and think."</i> (CSU research project 4th patient after completing therapy)</p> <p><i>"He knows his stuff but he doesn't stay there when he is working with a patient. He also has his spiritual way of looking at things and basically has a lot of trust in human beings."</i> (Lesley, video documentary interviews)</p>
	Being drawn in by the clinician's self-and other belief	<p>The person is willing to engage because the clinician inspires confidence in the person's own ability to get better. That confidence is understood by the patient as an expression of the clinician's own training, experience and personal beliefs. The authenticity is expressed in the clinician's ability to listen deeply and draw on relevant skills and knowledge as required for the individual in front of them. This is often contrasted with previous experience with the health system which was rigid, inflexible and 'by numbers'.</p> <p>(I am considering expressing this theme on a continuum of care experience from by numbers to 'authentic care experience'.)</p>	<p><i>"He has a lot of trust in the integrity of your mind and your body working together and coming up with answers. And because he trusts it so much that gets communicated to the patient that 'Hey there is something going on here that makes sense.'"</i> (Lesely documentary project interviews)</p>

Overarching concept	Theme name	Definition	Illustrative quotes
	“It’s quite nice to feel more like a person”. The experience of being treated in a person-centred way.	This theme builds on the previous one and is expressed by interviewees as an experience of being seen as a person, often for the first time within the health system. The openness of the clinician for them to bring anything they deem relevant to the consultation process – not to limit themselves to what’s on their charts or medical records. They describe feeling ‘not alone’, ‘secure’ ‘safe’ and ‘seen as a person’ ‘trust’ in the therapeutic relationship.	<i>“He (previous specialist) only wants to know about your hives and the itchiness he doesn’t want to know would there be another reason why it has been brought on. I mean that has never been part of the, I mean initially I did have about 40 minutes of them I think but from there on, and I try and get in a little bit of what is happening because I think that is relevant to what I am experiencing but he is on a very limited like 10 minutes tops and kind of if you are still saying that I did he is kind of at the door saying I will see you in 2 weeks and he has already typed out your letter, I just find it, the whole process was kind of impersonal. See I shouldn’t say that but it is an impersonal kind of way....So it is good to be able to come in for someone to take on board what else might be happening in your life and if somebody could put the two together and then say well how about we, you need the antihistamines for a wee while to try and get it under control I guess but there might be other ways that we can address.” (CSU research project 3rd patient after completing her sessions.)</i>
	The importance of working with someone who is medically trained	In some cases this was an important element of them being willing to ‘trust the process’. More so in the video project, because in the hospital project it was a given they were working with a medically trained clinical. All of them engaged with the work with Brian on the basis that he was a trained physician (only one interview was with another psychotherapist which Brian referred the person to). A sort of an important entry point and willingness on behalf of the patient to enter into this different dimension of a therapeutic relationship for their chronic illness.	<i>“I guess it always sits in the back of your mind that you know that he’s a specialist in the immunology field so I knew that the information he was giving me in terms of tips and tricks on how to not itch so much and things like that were actually coming from a knowledgeable point.” (2nd patient in CSU research second interview after completing her sessions)</i> <i>“But at the same time I knew that he had expertise in the traditional sort of medical type stuff as well. Which I don’t know I guess looking back I sort of had faith in the fact that he had both, expertise in both sort of areas yeah. He was coming at it from a different angle but he also had the other, you know I didn’t feel like he was a quack in anyway, or anything like that.” (JL, Video documentary project)</i>

Overarching concept	Theme name	Definition	Illustrative quotes
	When the 'baggage' of psychotherapy is or isn't present	<p>When the therapeutic process is introduced in the context of the clinician also being a psychotherapist, in more cases than not, this is encountered with a deeply held bias against it.</p> <p>However, those who enter a therapeutic relationship in the hospital (during CSU research project) and in the interview it seemed they weren't aware it was psychotherapeutically based, despite it being communicated in the research information flyer (only one recognised for what it was because she had a lot of prior therapy) they were curious about the experience and why it felt so different. To them this experience and talking about their illness in this way seemed quite natural and they welcomed it even though they did find it emotionally difficult and draining.</p>	<p><i>"I am going to say no because I don't even think I need anything to do with psychotherapy because I always thought that that kind of thing was for people who had mental problems. And I thought of myself as being very stable...And the idea that I needed some kind of treatment for my mental condition I thought 'Nah that's not on.'"</i> (Lesely, video documentary interviews.)</p> <p><i>"So that (the psychotherapy aspect) was sort of a surprise but actually it was really, it was interesting and even the first session I sort of remember that I got enough out of it and thought that it was intriguing and thought that there might be possibilities and was quite open to possibilities so I kept going."</i> (JL, Video documentary project)</p> <p><i>"I was quite, not sceptical but I just, to begin with I wasn't really sure what I was in for. It was quite scary but I'm really pleased I did it because, well I'd say it's probably the most helpful thing I've done really. Nothing else seemed to work and I'm really, I'm happy with the result and I believe a lot more now about mind and body I must admit, the approach."</i> (CSU research project 4th patient after completing therapy).</p> <p><i>"(Answering what he thinks of this type of approach) I think it's quite good actually, being able to talk to somebody without any repercussions so to speak. In other words no family arguments or that type of thing. I think it's quite good in that respect."</i> (1st patient – male, 1st interview after 2 sessions, CSU research research).</p>

Overarching concept	Theme name	Definition	Illustrative quotes
The person's own sense making: What made me get better? This is distinct from the group above, as it is concerned with the people own views of what was at play for them.	"Like a door into understanding"	This reflects the person's own understanding of what happened in the therapeutic interface that helped them get better. Many interviewees commented that they already had some vague sense that their illness was related to the way they lived their lives. This comes across as a pre-articulated sense. It appears as if they think that the therapeutic experience facilitates their ability to verbalise, contextualise and make sense of this pre-verbal understanding. And that this process resulted them in getting better even though they can't quite pinpoint what happened. Importantly, that inability does not seem to be an issue for them.	<p><i>"Because along I'd been, and I did have a tie, I'd recognised there was a tie-up between how my body was feeling at the time and there were situations where it would be triggered by extreme tiredness or stress or if I got sick. That was the other thing, any illness." (CSU research project 4th patient after completing therapy).</i></p> <p><i>"But there was a sense that was different from other times in that I didn't think "now I will be better" or "from now on things will feel better because this has happened" it just was, it just was better. It was like stepping into a pool of light or, I don't know how to describe it, it just was better. And since that time I have no reoccurrence of the cancer and there have been some very sad things that have happened in my life since but no more." (Christine Video project interviews)</i></p> <p><i>"But look I am an optimistic person by sort of nature and stuff but I had got myself into such a rut that I wasn't really able to be myself. And so after the sessions I just started to get better. I left the relationship, I put plans, I just kind of took charge of my life really and put plans in place to move on and leave, get a job somewhere else. And when I look back now everything sort of just fell into place and it has been pretty amazing. And all those things, I don't think they could have happened if I hadn't of seen and been with him." (JLVideo project interviews)</i></p>

Overarching concept	Theme name	Definition	Illustrative quotes
	"I need to take control of how I deal with things"	Following on the theme above, related but separate. It seems that through the door onto understanding, patients describe how the therapeutic process harnessed and crystallised that understanding, resulting in behavioural shift by them. The interviewees describe that process as one where they 'made sense of things', learnt how to take charge, control and responsibility.	<p><i>"that I need to somehow take responsibility, not responsibility, control of how I deal with things"</i> (Karen Project 3rd patient after 2 sessions)</p> <p><i>"So that was, well looking back the sessions with Brian gave me the courage really and the skills to get out of that whole situation.... Oh yeah my body you know I just started to feel, my illness, my rheumatoid arthritis started to not be so significant. I started to get on top of that and I started to be able to be more active. But also I had already decided that it wasn't going to be so important, it wasn't going to rule my life in the same way as it had. You know I started to take some responsibility for it myself too without having seen and talked with, without having those sessions with (names male) I wasn't able to do that."</i> (JL Video documentary interviews)</p> <p><i>"I have never felt that that was kind of not my right but it was something that I didn't do to say I am tired, I can't do any more, I have never kind of considered myself to that extent I suppose or felt that I owed myself to do that so that was one of the biggest things I took away from it that it is okay to do that.... Yes, you know like I said I have taken on board what we spoke about and I will attempt to revise the way I deal in situations"</i> (CSU research project 3rd patient after completing sessions)</p>

Appendix J: Evaluation overview of interview guide

Interview questions used in the pre-pilot (re worded for simplicity):

When were you first diagnosed? How long did you have the symptoms beforehand?
Tell me about your treatments
What strategies did you use to get well before seeing this clinician? Were they helpful?
How do you feel now? Any symptoms? How often do you get checked? Is the illness impacting on how you live your life? If so how?
What did it feel like? (seeing this healthcare person?)
How did you find this way of being treated? (prompt) Was it different from the other doctors/specialists you have seen before? How?
Did anything change for you since you've seen them? Thoughts? Feeling?
Relationships? Other?
Would you recommend it to other people who are experiencing chronic illness? Who would you recommend it to? Why? Why not?

From secondary analysis:

Did any of the other medical people talk to you about the connection between emotions and physical symptoms? Do you think it is important that more do?
Role of stress/emotions in their illness from their perspective.
What did it feel like talking about your life to a medical person? (paraphrase)
Would they have found it beneficial to be told about what we know about mind-body connections in the past? How can this best be done?

Questions around length of experience needed:

Need to phrase a question around the stigma associated with 'psych' type consultation (emerged strongly in analysis) how they felt and how to best deal with that?
Are there any dangers they see if more clinicians adopted this approach? How might we overcome them? How can they be mitigated?
Either ask to bring an object that represents their experience with the clinician or ask them if they were to choose an object which represented the relationship with the clinician what would that be and why?

From discussion with Professor Sally Thorne:

What do you think other medical practitioners can learn from this way of treating chronic illness?
If you had a magic wand, how would you change the way the system treats people who suffer from chronic illness?
What was most powerful/helpful/important for you from this experience?
What was most difficult for you in this experience?

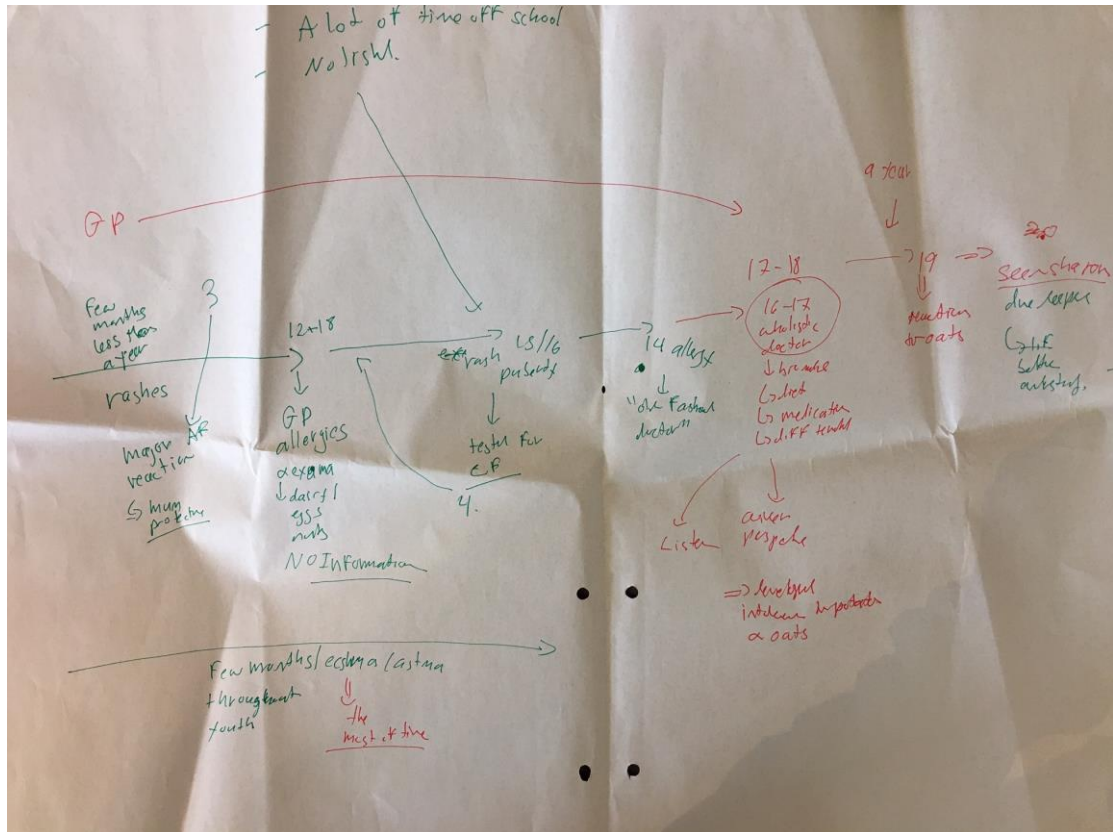
After the supervisory meeting on 10 June, 2016, we talked about exploring more in-depth the following aspects which were added to the interview guide from the ninth interview onwards:

Explore areas of readiness? Is it necessary for the patient to think like that for the experience to be successful? Will it work for anyone?

Exploring listening: 'What did they ask you about that was helpful?' or 'When s/he listened like that what were you able to say?' or 'What were you able to say that you could not have said to other clinicians?'

Looking back, what made your suffering throughout worse? What helped alleviate it?

Appendix K: Timelining

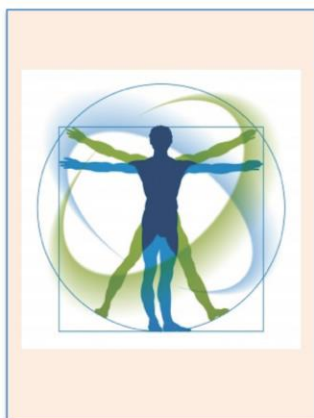


Appendix L: Research flyers and detailed information sheets

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

ARE YOU BEING TREATED FOR A CHRONIC ILLNESS BY A WHOLE-PERSON ORIENTED CLINICIAN UNDER THE IMMUNOLOGY DEPARTMENT?



Would you like to be part of a research on how the whole-person care approach can inform other clinicians about caring for people with chronic illness?

This research seeks to understand the experience of people with chronic conditions who were/are being treated by whole-person oriented medical staff. These medical clinicians operate from a point of view that illness has to do with every aspect of our lives. My research is mostly concerned with how your experience can inform doctors and other clinical staff about improving the care for people who suffer from chronic conditions.

What will happen in this research?

The research will involve an interview about your experiences of care. It will be a relaxed discussion that could last up to two hours.

If you are one of these patients and would like to receive more information about this research please contact me at:

e-mail: galia.bar-hava@xtra.co.nz

phone: 022 095 2549

Alternatively: Your clinician can pass on your details to me to contact you directly.

Please write your details here if you want me to contact you.

Name:

Email:

Phone-number:

BEING SEEN AS A WHOLE

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

Participant Information Sheet

Monday, Thursday, 25 February 2016

Invitation:

My name is Galia Barhava-Monteith and I am a Doctoral candidate with AUT's Faculty of Health and Environmental studies. I would like to invite you to participate in my research, which will contribute to my Doctorate. This research seeks to understand the experience of people with chronic conditions who were, or are being, treated by whole-person oriented medical staff. These medical clinicians operate from a point of view that illness has to do with every aspect of our lives. My research is mostly concerned with learning about your experience to inform doctors and other clinical staff about improving the care for people who suffer from chronic conditions.

How were you identified and why are you invited to participate in this research?

You are invited to participate in this research because you expressed an interest about this research after receiving the flyer from your clinician and you can converse in English with me.

What is the purpose of this research?

My research comes from a very personal place. In 2010 I was diagnosed with a chronic autoimmune illness and after undergoing chemotherapy in the immunology department in Auckland Hospital as a day patient, I started working with a whole-person oriented clinician. Following my own personal experience, I want to learn from the perspectives of other people who have experienced this care, so that this research can help inform about this approach and how it might be improved.

The key reason I am doing this research is to influence the practical care of people with chronic illness.

YOUR RIGHTS:

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question
- Withdraw from the study at any stage prior to completion of the data collection
- Ask any questions about the study at any time during participation
- Provide information on the understanding that your name will not be used unless you give written permission

What are the benefits?

This research will serve to inform doctors and clinicians of the patients' perspectives of their own treatment.

My aim is that this research will help further inform and possibly enhance the way people with chronic illnesses are treated.

This research will contribute to informing people who are living with a chronic condition of the whole-person approach to healthcare.

- Ask for the recorder to be turned off at any time during the interview

What will happen in this research?

The research will involve an interview with myself about your experiences of care. It will be a relaxed discussion that could last up to two hours. I would like to audio-record our conversation.

During this interview, we will talk through your diagnosis and illness for the first part of the interview, and your care experience for the second part. I would also like to invite you to bring an object that comes to mind when you think about your treatment experience. You can bring anything that makes sense to you. It can be an object, a photo, a book, a poem or piece of art. I might ask you to photograph the item so I can refer back to it in my analysis.

Following the interview, I will transcribe the audio recording and analyse it. I will also discuss my emerging thoughts and reflections with medical clinicians to ensure they “make sense” to them. They will see a summary of my thinking. They will not know who has taken part and I will not discuss individual patient interviews with them.

If you have any questions, we can discuss them in our phone conversation prior to setting the interview up or, if you prefer, I would be happy to meet with you to answer any questions you have.

Once the interview is complete, with your permission, I may contact you again if I have any further questions or need to clarify something.

What are the discomforts or the risks?

You might find it emotional or hard to ‘go back’ and talk about these experiences, which may by now be well behind you. You may be concerned that the health practitioner who referred you will find out what you said about them, or that other people reading or hearing about my research will be able to identify you.

How will the discomforts or the risks be alleviated?

Everything you say will be completely confidential and only I will know the identity of the patients I interviewed. Any emerging findings that I will share with thoughtful clinicians will be shared in an aggregate manner without any ability for people to identify individuals.

I am a psychologist by training and I have many years experience as an executive coach. I will do my very best to provide a safe environment for you to share your story with me. At any point during the interview, should you wish for us to stop we can do so.

If sensitive or distressing issues do arise during the interview, and you would like to discuss these with someone after the interview, you will be able to access free counselling for a maximum of three sessions. These counselling sessions must be in relation to issues arising from your participation in this research. Appointments can be made over the phone on 921 9992 for the city campus counselling service or 921 9998 for the North Shore campus counselling service.

How do I agree to participate in this research?

You can either email me on:
galia.bar-hava@xtra.co.nz

You can also call me on:

022 095 2549

Or if you prefer, your clinician can pass your details on to me and I will contact you directly.

Will I receive feedback on the results of this research?

Absolutely. I plan to disseminate the interpretation of my findings widely. I will be emailing all my participants a summary of my findings once I’m done. I intend to offer public presentations of my findings, which you could choose to attend. You could also read about what I am doing on my personal account on twitter @galiaBM

How will my privacy be protected?

In order to respect your privacy and confidentiality:

- All details that could potentially identify you will be removed from any research publication
- The data will be kept for six years following the completion of the research in a secure storage at AUT University (North Shore Campus)
- Everything that you tell me will be kept confidential and not be reported in a manner that could identify you, except in the unlikely case that you reveal significant illegal activity, in which case I may be obliged to report it.

For more information about this research contact:

Galia Barhava-Monteith

Galia.Bar-Hava@xtra.co.nz

022 095 2549

What are the costs of participating in this research?

In the interview itself, the cost to you will be up to two hours of your time. If you give permission to me to follow up with you after the interview, this might mean another 30 minutes phone call and/or a further face to face interview to clarify certain things.

What opportunity do I have to consider this invitation?

You have two weeks to consider this invitation.

Project Supervisor Contact Details:

Associate Professor Nicola Kayes (see contact details on side-bar)

Approved by the Auckland University of Technology Ethics Committee on type the date final ethics approval was granted, AUTEK Reference number type the reference number

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor,

Associate Professor Nicola Kayes

Phone: +64 9 921 9999 ext 7309

Email: nkayes@aut.ac.nz

- See more at:

<http://www.aut.ac.nz/profiles/nicola-kayes#sthash.Sgkspq92.dpuf>

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

I would like to be contacted about this research:

Name:

Email address:

Or I prefer you call me on:

BEING SEEN AS A WHOLE

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

Participant Information Sheet

Monday, 11 November 2015

Invitation:

My name is Galia Barhava-Monteith and I am a Doctoral candidate with AUT's Faculty of Health and Environmental studies. I would like to invite you to participate my research, which will contribute to my Doctorate. This research seeks to understand the experience of people with chronic conditions who were, or are being, treated by whole-person oriented medical staff. These medical clinicians operate from a point of view that illness has to do with every aspect of our lives. My research is mostly concerned with learning about your experience to inform doctors and other clinical staff about improving the care for people who suffer from chronic conditions.

How were you identified and why are you invited to participate in this research?

You are invited to participate in this research because you participated in similar pilot research on this topic with Dr Lindsay in the Immunology department in Auckland hospital between February 2011 and February 2012 and I am seeking to re-analyse your interview transcripts in phase 1 of my doctoral research.

What is the purpose of this research?

My research comes from a very personal place. In 2010 I was diagnosed with a chronic autoimmune illness and after undergoing chemotherapy in the immunology department in Auckland Hospital as a day patient, I started working with a whole-person oriented clinician. Following my own personal experience, I want to learn from the perspectives of other people who have experienced this care, so that this research can help inform about this approach and how it might be improved.

The key reason I am doing this research is to influence the practical care approach to people with chronic illness.

What are the benefits?

This research will serve to inform doctors and clinicians of the patients' perspective of their own treatment.

My aim is that this research will help further inform and possibly enhance the way people with chronic illnesses are treated.

This research will contribute to informing people who are living with a chronic condition of the whole-person approach to healthcare.

What will happen in this research?

With your permission, I will re-read and analyse the existing transcripts from the interviews you have undertaken with Dr Lindsay. You will not be asked to be interviewed again or to give any of your time for this

How do I agree to participate in this research?

By indicating to Doctor Lindsay that you are happy for your transcripts to be re-analysed by me.

research.

What are the discomforts or the risks?

There are no discomforts and risks for you. You don't have to agree to using your transcripts if you don't want me and my supervisors to read your interviews.

How will my privacy be protected?

Your interview transcripts will be treated confidentially. Because I will use false-names in all my subsequent work, your identity will only be known to me. I will have only one password-protected document on my personal desktop which will link your real name with your pseudonym.

What are the costs of participating in this research?

There are no costs to you.

What opportunity do I have to consider this invitation?

You may wish to speak to me about this research before consenting to the use of your interview data. Should you wish to speak to me, please email me on the email address provided on the side bar and we can arrange for us to talk by phone.

Please let Doctor Lindsay know within two weeks' time whether you are happy for me to use your transcripts.

Project Supervisor Contact Details:

Associate Professor Nicola Kayes (see below)

Will I receive feedback on the results of this research?

Absolutely. I plan to disseminate my finding widely. I will be emailing all my participants a summary of my findings once I'm done. I intend to offer public presentations of my findings, which you could choose to attend. You could also read about what I am doing on my personal account on twitter @galiaBM

For more information about this research contact:

Galia Barhava-Monteith
galia@gbmconsulting.co.nz please note this is my work email and the one I check most frequently.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor,

Associate Professor Nicola Kayes

Phone: +64 9 921 9999 ext 7309

Email: nkayes@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Approved by the Auckland University of Technology Ethics Committee on
Tuesday, 24 November 2015
Reference Number 15/358

Appendix M: Ethics approval letters

AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics



24 November 2015

Nicola Kayes
Faculty of Health and Environmental Sciences

Dear Nicola

Re: Ethics Application: → 15/358 Being seen as a 'whole': What can clinicians learn about caring for chronic illness from persons' experiences of non-dualistic healthcare in a biomedical setting?

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 23 November 2018.

This application is approved in stages and we advise that locality authorisation from participating DHB's is required before AUTEC's approval for data collection will be given.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- → A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 23 November 2018;
- → A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 23 November 2018 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research.



Research Office
Level 14, Support Bldg
Auckland City Hospital
PB 92024, Grafton, Auckland
Phone: 64 9 307 4949 Extn. 23854
Fax: 64 9 307 8913
Email: mwoodnorth@adhb.govt.nz
Website: www.adhb.govt.nz/ResearchOffice

11 December 2015

Galia Barhava-Montieth
49 Baildon Road
Grey Lynn
Auckland

Institutional Approval

Dear Galia

Re: Research project A+ 7005 (Ethics ATEC 15/358) Being seen as a "Whole": What can clinicians learn about caring for chronic illness from persons' experiences of non-dualistic healthcare in a biomedical setting

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the ADHB Research Review Committee
Dr Mary-Anne Woodnorth
Manager, Research Office
ADHB

c.c. Anthony Jordan, Brian Broom, Miriam Hurst

Appendix N: Primary analysis memo referring to the secondary analysis

WHAT'S GOING ON HERE?

Complicated and dangerous symptoms, bounced around the health system significantly. Was referred to Immunology by the hospital system. Have suffered in the past from mental health issues. Such self insight after only once with WPTA clinician, She repeated she had mental illness a few times, clinician helped her realise that the physical symptoms are worse when she suffers from specific 'mental' symptoms. She sounds tearful when she says that but also relieved, she laughs when she finishes saying that (won't get that on the script)

REFLEXIVE THOUGHT?

As I am listening right at the beginning, I am struck by why I spend so much time "collecting medical history" because it is part of their history and they are in fact experiencing an actual biographical disruption journeying in and out of the medical system, a barrage of tests and probes, can't live a normal life. Somehow it isn't coming through the literature on how real this is, also in the secondary analysis they didn't spend a lot of time on the impact of the illness on the lived life and I really want to bring it to life in my own PhD so that the reader can viscerally feel what it is like to bounce like that in the medical system. Certainly people who are spiritual are more connected to the approach but not just them. Interestingly even though she believed in links she never made the connection with herself. Enhances the importance of the educational side. I am really heavily drawn to the role of the clinician as an educator.

INTERPRETIVE ANALYTICAL

Her story is particularly important as the other clinicians made all the physical connections but despite knowing her mental health history they haven't addressed these links.

Something here as well about the link between professional identities, the way clinician interact with patients, and the experience of patients. She was very open to connections but didn't make the connection herself. She says at about 22 minutes in that "it isn't something that only happens to other people" so something about the health system that stops them from making the connections. There is something about how this approach gets people to take responsibility of their own health and life style, that could be important to linking the approach for the patient empowerment, self medication etc movement and argument in the context of chronic illness. By linking everything together for them, they appear to be making sense of their own condition, which gets them to take accountability and control

THEMES

Listening, or not, talking "a bit of a chaotic journey" Bouncing in the health system, complicated histories/ hard to diagnose/ different specialists dealing with different symptoms "no one knew what was going on" "very frustrating" Chronic illness is a biographical disruption similar to the descriptions from the secondary analysis: life disruption Disruptive lives: twice a week for hospital, high personal costs. Experience of immobilized by the health system: almost felt really dumb. I was so shocked by what was happening. (repeated that many times) and the medical response is to talk her parents. "Psychotherapy as well as medical treatment" the psychotherapy as a hopeful experience coming out feeling very hopeful.

"it was very interesting, she opened my eyes up to how my mental health has a lot to do with my physical health. my stresses cause flare ups"

METHODOLOGICAL

Very interesting, she herself talked about the connection with her OCD getting out of control and the physical symptoms flaring up. But when I directly ask her about the connection between the emotions and the symptoms directly she can't answer. perhaps drop that question and explore more with how? what? where do you notice etc? its like they can see the thing from the corner of their eyes but not when they look directly at it.

**Appendix O: Illustrative extracts from the complex questions
analytical table focusing on listening**

Topic	Analytical questions asked	Quotes that speak to this question	Emerging analytical thoughts
Listening	<p>What is it that the clinician is listening to, which is helpful?</p> <p>(speak to content and/or intent)</p>	<p>“So it was good I felt like I was being heard suddenly. That someone was actually listening to the whole thing.” (Amy)</p> <p>“Because I think he realised all along well it wasn’t difficult to realise it, what do I do with the pain in the meantime? What do I do with the pain before I can hear that message? So he first dealt with the pain and then I could hear the message.” (Lorie)</p> <p>“But with (WPTA psychotherapist) it was right off the bat. I felt listened to, I just felt comfortable to be able to talk about those sorts of things.” (Jason)</p> <p>“It was like some relief finally. Like it was just everyone that I had talked to for four years just didn’t have the time or the understanding or the, they weren’t listening to the full picture. They were only listening to their part. Their part to play in the picture. And if they couldn’t see the answers straight down the line, then it was “Sorry, I can’t help you. Moving along.” (Amy)</p> <p>“I: So what is it that she does?</p> <p>P: She never looks like she drifts off, she attends. She has an ability to concentrate on what someone is saying ... To listen when someone talks for an hour, I have done that but it’s actually quite difficult. To listen for an hour without saying anything.” (Lorie)</p> <p>“Um, I’m not going to name names but she definitely was very attentive and very switched on in regards to listening to me. And so was (doctor) she was very attentive and listened to what I and listened to what I had to say.” (Claire)</p> <p>“An hour a session. So when you look at the GP it’s 15 minutes, bang, bang, bang, thanks, cool, bye. Pay your bill on the way out. Naturopath would have probably been a little bit more engaging, but once again lets quickly resolve this, that’s what you can do. So that’s probably, I think having the time to get to know me and my personality and then dive into the food stuff just made you feel like she is not rushing, she is not rushing to provide solutions she is getting everything about you and forming plans out of that. So yeah, so there was no pressure. That’s what I think. Because of time constraints.” (Jonah)</p> <p>“Yeah but it’s really good because she does pay attention to what I am saying. Like asking questions about my childhood and all that sort of stuff like I said before. So yeah it feels like I am getting a lot of value.” (Ben)</p> <p>“I think she just noticed when what I was saying connected to what she knew. So for instance if I was saying something negative about myself she may of just asked a question like ‘Do you know what you are feeling</p>	<p>Both content and intent are important. What I am seeing is that the people can tell if the clinician is truly open to hearing the story that they want to get across, be it a WPTA or any other clinician (WPTA can also be experienced as not listening, as in Jason’s interview). True listening is experienced as a mark of the respect of the personhood of the patient. That sense of not being rushed or pushed.</p> <p>From Jason’s memo: “What is also emerging that a big part of building the trust (in this interview and in Ian’s) is listening and knowing how to listen authentically... Also particularly important in the context of someone who is suffering from a chronic illness for the foreseeable future. So that’s a different aspect which was overlooked. The prevalence of the symptoms is really strong and the need to be listened and respected.” (April 2016)</p> <p>Methodologically, I believe that my spending time at the beginning of the interviews to hear their illness story has really served to create that sense of respect and enhanced the quality of the interview.</p>

Topic	Analytical questions asked	Quotes that speak to this question	Emerging analytical thoughts
		<p>when you are saying that?’ And I would say, and I would express the feeling and she would explore the feeling and the reasons for the feeling. She mostly concentrated on helping me actually recognise what I am feeling. And I think as medical professionals I think we do suppress our feelings quite a lot and we concentrate on the scientific aspects of the disease.” (Lorie)</p> <p>“So if I were a doctor I would be very much interested in not just what is the symptom but what is the underlying cause, you know? So it is very rare for me to actually find a GP who would be interested in that. Like it is not often that you find the GPs that you know ask the further questions.” (David)</p> <p>“I: And what was it like speaking with (WPTA hospital clinician) about those very intimate details in the hospital setting with the specialist? What was that like?</p> <p>P: Well of course you were in the little interview rooms so you were being quite private. She was very approachable and very calm and put you at ease, I don’t know what to say, you know put you at ease and made you feel safe.</p> <p>I: How did she do that?</p> <p>P: Just her tone when she was talking. Sometimes she would do diagrams and the way she would explain them were quite simplistic, you know she used English terms rather than medical terms. She was always very much into that you know being, using English rather than medical terminology which was very good. And she was just very relaxed and it was a thing of you could feel the confidence she had in herself and I think probably the confidence she had because of doing it for so long that she knew what she was talking about.” (Beth)</p> <p>“I find it quite daunting to tell you the truth. I do I find it quite daunting. Someone told me today I am a good listener and that she enjoys talking to me. But I don’t feel, I actually don’t feel I always know what to ask. What question to ask to bring out that information.</p> <p>I: Do you think that’s important?</p> <p>P: Of course that’s important you are never going to get there. I don’t think we will get there without the right question, without the right way of exploring.” (Lorie)</p>	
	Is it important from the patient perspective what the clinician is listening to?	<p>“Well I feel like when I went there she pretty much just got my whole story of who you are pretty much from birth all the way through to where I was. And sort of just looked at all these other factors that no other doctor had ever looked at before. And I think I just came out feeling really good about it <i>because I felt like I got every point that I wanted her to address across</i>. Like she would actually really listen. And think addressing just sometimes the symptoms is always a good view, I think addressing the causes and like maybe different factors, having a wider perspective is a good thing to do.” (Ben)</p> <p>“He would listen to me, then he would say ‘When you are talking to me the picture I am getting inside is a</p>	<p>Building on the comments above, I believe the interviews and these quotes illustrate that it is important from the patient perspective that the clinician listens to the story that the person/patient wants to tell. They can sense very quickly if the clinician has an ‘agenda’ in listening. Be it only for the symptoms that fall in their</p>

Topic	Analytical questions asked	Quotes that speak to this question	Emerging analytical thoughts
		<p>picture like this’ he would tell me a picture story or another story that linked in with what I am saying which often had a hard moment for me like I would go ‘Oh’ and I would suddenly get it. For instance, the very first picture story I remember him telling me is when I was grappling with the process of my colleagues at my previous job.” (Lorie)</p> <p>“I: And what is it about her listening that you know she’s attentive? P: She has a remarkable ability to take the information I am telling her and process it in a way and then present it back to me that is very meaningful to me. I: What is it about it that it’s meaningful? P: It sounds likes she has heard what I have said. Interpreted in a way that even I don’t understand. Then asked a question that helped me see the point. Or she has actually given me a little bit of instruction. Just plain straight up given me a little instruction. Or she’s told me a story that’s brought light into my world, what I was talking about. The situation or the feeling. So she has listened to me. So you can listen to someone and the person can <i>feel heard but not helped maybe</i>.” (Lorie)</p> <p>“It made sense for me. It worked for me because she basically was, she was in a sense praying to the converted because I thought there is, I need other assistance other than ‘Hey change your diet.’ I need possibly people to talk to I need people who would listen to me and so I thought I would give it a go and see what happens.” (Steve)</p> <p>“Because she is from China, in her line of work, predominantly the people she’s seen with cold urticaria had an underlying medical condition. And 95% of that time it was cancer that was laying dormant. So I’ve always remembered that because I have always thought, well because I am healthy, other than these rashes every time I get wet, I have carried that on and I have told the doctors, I have told (WPTA clinician) that she’s made me do all these blood tests. But still in my mind, I don’t know I haven’t really been reassured yet. In our family we have a lot of cancer. Like a lot of people dying of cancer, breast cancer, lung cancer, testicular cancer. Yeah and tumours. So it’s kind of like I feel like it’s my turn soon.” (Jason)</p> <p>“She’s, I feel like she really listens to me, she doesn’t just throw questions at me like a lot of previous people I have seen did. It’s just so many questions it’s just I got lost. She listens to me and she’s a very warm person, she’s very inviting. She is very warm, she’s inviting and she just has a present about her that makes me feel very comfortable. She’s not intimidating, she’s not sort of sitting there legs crossed just you know, I mean she does write things down but her mannerisms and the way about her makes me feel very comfortable as opposed to some other people who I have seen who seem very you know like I’m just another product, ‘You have an hour, hurry up, bye bye’ does that make sense?” (Claire)</p> <p>“She just got it, she just understood. She just understood. Yeah.” (Jonah)</p> <p>“With (WPTA psychotherapist) she just listened really. <i>She didn’t try to put words in my mouth or make me</i></p>	<p>area of expertise or be it if they have a WPTA agenda.</p> <p>A lot of the sense of hopefulness comes from the connections the clinicians made for them, the ‘coaching’ or ‘educational’ component of the whole person. For the listening specifically what is very powerful for me, is about clinicians listening to the story the patient wants them to listen to. And that is achieved through their questioning technique, the type of questions they ask and their gesture and how they make the patients feel. The patients feel unrushed, respected, and very importantly, they feel both safe and being in safe hands.</p> <p>Note that I chose Jason’s negative example of not feeling listened to by the WPTA hospital clinician because my interpretation of it and his interview is that he wanted to be listened to what he wanted to bring across, his symptoms, medical history of the family – and he experienced as if the clinician only wanted to listen to certain aspects (life experiences, emotional trauma).</p> <p>THEMES: <i>Feeling heard and helped.</i> Goes beyond listening – the feeling that they are actually being heard, that the clinician is open and inviting for them to tell the story they want to tell, that they don’t have an ‘agenda’ in listening (be it, focus on the symptoms or focus on psychological processes). But it goes beyond that, what the clinician is</p>

Topic	Analytical questions asked	Quotes that speak to this question	Emerging analytical thoughts
		<p><i>think differently.</i>" (Jason)</p> <p>"And then I come here and I sat down and then she asks me questions like 'Ok so what was your birth like? What are the members of your family and what are they like and what is their health like? Have you had like, how's your mind state? Have you had any stress?' If I did say something like an event was happening she would say 'Ok how does that make you feel?' Stuff like that. <i>And like I think it's, you know it makes me feel like I am addressing aspects of my illness a lot more and I am getting like you know, I am in better care and I am making more progress.</i>" (Ben)</p> <p>"Like even the elevator door for closing the elevators, that's a placebo because you feel like you are in control because you push the button and you are like 'Yeah that's going to close' but it's like you know it closes when it closes. It's got nothing to do with whether we push the button. But it relieves stress right? Or you know like when people have their little rituals those are slightly like placebos like you know I am wearing my lucky shoes, oh ok, so you are lucky and you feel more confident and all of that. <i>So maybe this approach could also be a little bit of that. Where you know she makes me feel good talking to her so therefore I feel better anyway.</i>" (David)</p>	<p>offering in response, a thoughtful question, or a story.</p>
	<p>What made the listening relevant and crucial in some way?</p>	<p>"And asking me about like how I was as a baby, like how I, because when I was born I had like an emergency C-section because my mum, the umbilical cord was wrapped around my head a few times. So she (hospital WPTA) was asking all questions about that. And all sorts of questions like stress and stress in my family environment and all that sort of stuff. And to do with my skin. And the reasons why I make different food choices as well. And she sort of just, it was really interesting because I actually like growing up I'd actually thought that, I had always had this thought that maybe my mind like has a lot to do with like how I react with especially my (diagnosed condition). Because I notice, especially when I go through times of stress, it just flares up and I just scratch like crazy and also in terms of just like food choices and stuff too." (Ben)</p> <p>"So when I spoke with WPTA psychotherapist, she was able to listen, hear my story and then she, never changing it but always offering explanations on how, not just saying 'This is why it's happening and this is what you need to do.' But she always, well both of them they always talked it through until eventually in my mind I was happy with what I was hearing, I wasn't told 'Take this or do that and you will be better, see you later.'" (Jason)</p> <p>"And then I come here and I sat down and then she asks me questions like 'Ok so what was your birth like? What are the members of your family and what are they like and what is their health like? Have you had like, how's your mind state? Have you had any stress?' If I did say something like an event was happening she would say 'Ok how does that make you feel?' Stuff like that. And like I think it's, you know it makes me feel like I am addressing aspects of my illness a lot more and I am getting like you know, I am in better care and I am making more progress." (Ben)</p>	<p>The questions asked and how they 'ignite' the patients' thinking about various aspects of their lives and how they interact with their symptoms. Tapping into that 'pre-verbal' understanding patients come with around their own understanding of their illness. The questions and the subsequent listening are what makes it relevant and crucial. It appears to me about the authenticity of the interaction – the genuine curiosity in them as a person, without rushing them or pushing them into a regime. From Ben's memo: "Here, the listening he experienced first was with the first 'holistic' paediatrician. H describes it as finally being able 'to get everything he wanted across'. Feeling satisfied that he can talk about the whole of his life. With the WPTA clinician, she only started asking him about factors outside her immediate expertise in the second session, which he found really refreshing because he felt it was made more valid?"</p> <p>Grounded? Because of her professional</p>

Topic	Analytical questions asked	Quotes that speak to this question	Emerging analytical thoughts
		<p>“Yes I believe so yeah. I mean she asked the questions but I believe she knew. She had read through and obviously asked guided questions. So I suffer from (names mental conditions she has been diagnosed for), of which I am all on medication for, have been for the past 14 or so years. It started from preschool years, I was born with it I suppose. But she thinks that the (diagnosed condition) comes out when I’m very stressed or very anxious or having an episode of being very depressed or my (names another mental diagnosed condition) is overwhelming me, my body seems to react with the flaring up with the (diagnosed condition). If that makes sense?” (Claire who has a ‘clear’ diagnosis)</p> <p>“So for me often those picture stories often brought through a breakthrough. Or he would tell me a story about someone he had met, no names mentioned or anything and this person had told him this story and that that story had reminded him of the one I was telling. So when I heard them tell a story about someone else with a story like mine it engaged my mind in a different way and allowed me to think to approach the mind-body aspect perhaps from a different angle.</p> <p>So instead of telling someone ‘I don’t know if you know this but your mind is capable of producing chemicals when you think negative things about your body or yourself or whatever those chemicals can actually send messages to your body and that can actually make you sick. So you need to stop it (laughs)’. That’s probably not the most helpful approach but yeah.” (Lorie)</p> <p>“I: Do you want to explain what that active sort of listening is from your perspective? P: I did. I did because she helps me interpret what I am saying. And I think that she has given me, I learnt in the sessions with the (immunologist) that sometimes you can be saying something but the message you are giving is actually something different. You can be saying something but you can be giving another message. She’s good at hearing that other message. I: And what is that other message? P: I don’t know quite how to put that into words. I don’t know really, I don’t know how to put it into words, but there’s probably a deeper meaning behind the words. A deeper meaning.” (Lorie)</p>	<p>expertise.</p> <p>Making the connections for him seems more important in this case than the act of listening or the experience of being listened to.” (June 2016)</p>

Appendix P: Analytical memo written after an interview with a participant who saw a WPTA physiotherapist

WHAT IS GOING ON HERE? A young woman with un-explained severe abdominal pains. She has had many de-humanizing experiences in the system, especially with her GP. The work she is doing with the clinician is around Breathing, and has elements of mind-body, it feels like the clinician is treading very carefully and gently with her. Crippling amount of pain, went down from being an A student to a C student. She broke into tears when told that it wasn't (a diagnosable condition she was hoping to 'get'), she thought people will think she is a liar, and she made the pain up. Feeling guilty for being in pain, powerless and afraid, and moving towards gaining ways to cope with it, practical ways, breathing. The clinician is working with her to becoming more accepting and curious, and to learning to accept the pain, being in pain while not having a 'cause'. It was a relief for her - to know she can still be in pain without a 'diagnosis'.

HOW IS IT SIMILAR TO INTERVIEWS WITH HOSPITAL PATIENTS? Very minimizing experiences from her GP who is saying that she is melodramatic and anxious about her university study. She is very dismissive - 'if it was that bad we would see that something is physically wrong'. Really wanted to be 'diagnosed'. The experience of 'no diagnosis' very devastating, like so much of the research on 'un-explained' symptoms. Anxiety is not real - you are making it up. Vivid descriptions of specialists being very focused on their own area of expertise. GP not prescribing her pain medication, extremely vivid description 59 minutes in - how she picked pain medication from her vomit! Relates to her life story - she had to protect younger siblings from unpredictable parent, clinician explained that being in this alert will have an impact. A validating experience of her pain in this context. Physical symptoms improved, not gone away, but she is able to continue with her life (very inline with a previous hospital story on the whole!). Blaming the patients for having conditions they can't diagnose. Making the connections very important for her.

IN WHAT WAYS IS IT DIFFERENT/UNIQUE? the breathing plays a big part here - and how the muscles speak to how tense she comes across, another way to demonstrate the impact of bringing in the body. - she explained how the muscles react and create a vicious cycle. The exercises, breathing and connection together all making a big difference for her. She has a way of saying that the pain is related to a psychological state but without judgment - she is just understanding while working on her muscles. A validating experience "that is really horrible, I am sorry you feel this way". A strong theme of acceptance without expecting them to get better - I read that elsewhere. but also offering a practical way to deal with it in how to breathe through the pain. The physical encounter - talking and touching, the touch making the person relax so that they are better able to talk about the things which really matter - linking it to the body "this part here is really tight" approaching things in a non threatening way 'lets be curious about this'

EMERGING THEMES? COMPLEX QUESTIONS TO ASK? the collaboration aspect of this relationship, utilizing the patients' expertise, allowing ownership of it, bringing it under control. excellent descriptions in -39 minutes, what are the things that set it off - a lot of relationship to patients empowerment and taking control here. Potential theme: developing/gaining mindbody self insight: exemplified by her story of how the pain got worse after the distressing encounter with the triage nurse but she was able to make the connections "make sense of what is going on, stress definitely has an impact on pain" (maybe an elaboration on 'connecting the dots') also in previous stories of how they now know to remove themselves from stressful situations. Focusing on getting better not being 'cured' by the clinician which results with the person learning to be more accepting of themselves. "yes you slipped backwards but you are not back to square one". Not judgmental: lets be curious about thing. What are the ways the clinician uses their professional identities to ground the experience?

REFLEXIVE MEMO

The key is that the GP said if the pain had no explanation to it is because it is her fault for being stressed. Stress is not real pain - a blame culture that creates obsessing, blaming her for her pain. But clinician says if you are stressed it makes things worse, so lets explore that, what we can do about it, how we can deal with it. Asking her what do you think: inviting collaboration. This really speaks to me and my approach. Stress is real, but what do we do about it???

Appendix Q: Questions for data analysis of interviews with participants who saw WPTA physiotherapists

- What is it that the physiotherapists do?
- In what ways is the experience of the WPTA physiotherapists unique?
- How does the body intimacy work?
- The clinicians are experienced as being mindful and present – how does the person feel this is the case?
- The experience is coming across as a collaborative one, where the persons expertise is taken into account, and they feel unrushed or pushed towards a specific agenda. What is it that the clinician does that helps them feel this way?
 - What does the concept of patients as experts in their own condition looks like?
- What is the importance of their specific story in this context?
- Where is the clinical focus? (is it about people becoming symptom free or about management?)
- How is the listening experience here?
- What about the role of stress? Is it addressed? How is it addressed?
- What are the ways the therapeutic experience is generalized by individuals outside the clinical context?

Appendix R: Overarching conceptual memos

Analytical memo (Wednesday, 2 November 2016)

Bringing the whole person of the clinician into the encounter, a necessary ingredient for the experience of being seen – not looked at.

This memo is written after the completion of 18 interviews, their individual analysis, ongoing listening and reading of the transcripts, and undertaking in-depth analysis, which led to the construction of the themes shared with supervisors in the October joint supervision meeting.

In my ongoing engagement with the data I have identified the importance of the ways by which the participants describe their perceptions of clinicians' rigid professional identity and boundaries, as severely limiting the care experience and often exacerbating their own sufferings. In my theme-based analysis, I termed "condition and expertise centred care" under the overall construct of living limited symptom entangled lives. However, with my ongoing reflection and engagement in the data, I have come to see this theme as an insufficient articulation of the impact on the person being treated, of experiencing rigid and heavily boundaried care.

It was through the analytical process of the interviews with people who saw the WPTA physiotherapists which have oriented me towards understanding the foundational aspect of the clinician's own orientation towards the individual in front of them, which is central, and dare I say fundamental, to the experience of being seen as a whole. I now comprehend the centrality of the ways by which the clinicians allow their whole, own self to be brought into the encounter, as a necessary ingredient for the person being treated to truly experience whole person-centred care, whether it is within the WPTA context or another in positive and healing care contexts.

To get to this appreciation, I reflected deeply on the descriptions of encounters with clinicians who seem to have very rigid professional identities as well as those whom the participants experienced as particularly healing, be they WPTA or others. Through this engagement I have also come to see the ways by which the people interviewed talked about their perceptions of rigid clinical boundaries and how these were experienced as blocking the healing from occurring. The more experienced and educated in the health system the person interviewed was, the more they commented on these boundaries.

For example, Jane, a woman in her thirties who was seen by a WPTA physiotherapist for severe neck pain, described herself as an anxious, on the go, person. During the interview she decides to contrast her experience of seeing the WPTA physiotherapist with her experience of seeing a psychiatrist in the past:

"P: She's very open. I've seen a psychiatrist in the past so I will use a comparison between the two of them.

I: That would be really helpful.

P; She is a lot more open than the psychiatrist is and you are expected to be more open with the psychiatrist.

I: How can you tell?

P: That she's open?

I: Yeah.

P: Well for example she doesn't, you know a psychiatrist will put you over there and they will be over here (Jane used exaggerated hand movements to exemplify over here

and over there) and there's a clear difference between them and you. They are asking you pointed questions and it's more to get down what, well from my understanding what they have learnt this is what could be wrong da, da, da, da, da. Don't get too close to the patient, it's an arm's length and it's a sort of superficial questioning I find, very expected line of questioning.

When you go and see her firstly she is a lot more engaging with you, she is a warmer person, she is just naturally warmer she has got more, she doesn't have that whole clinical approach she's like another human being. Like another friend that you would speak to but she's still a respected physiotherapist and you just get that vibe with her I don't know what else to say.

She's just got, she makes you feel comfortable. You walk in there, it's not staged it's not posed you just feel like you are in with one of your friends having a chat; and that you are two equal people and she's just going to use her expertise to help you out not that you were maybe, it's like she is going to work with you to help you solve your problem she is not going to solve your problem for you, maybe that's the difference with the psychiatrist and the patient versus her and her patients."

The key insight for me from this deep engagement was that for the person to experience their care as the care of their whole self, the clinician must also bring their whole own self into the clinical encounter. Patients (I am using this word deliberately here) are very sophisticated (irrespective of their level of formal education, age or ethnicity) in sensing if the clinician they are seeing is prepared to bring more of themselves into the encounter than the professionally prescribed identity. This in turn appears to influence the ways by which the patient is prepared to share their whole own self with the clinician, listen, and engage in the care relationship.

In her interview, Amy a woman in her mid-thirties who was referred to the immunology department for unexplained and extremely debilitating pain attacks contrasted her experiences in the health system in trying to 'get to the bottom' of the attacks before she saw the WPTA clinician in the department. In her journey, she took the time to tell me about all the healing encounters she's had with medical professionals which is illustrated in the quote below:

"Yeah all three of them (good clinicians) I feel like they saw me as a person, they didn't just see my condition. I felt, the endocrinologist I actually wrote a letter to him prior to going in with an overview because he was one of the last people I saw before I saw (hospital WPTA) so they both got a nice little packaged overview of my condition, like a referral letter but from my point of view. And he came out and he goes 'Do you mind if I just give you a hug?' and I was just like 'Oh thank you is that because this is really horrible?' You know? I felt like those three doctors, ok they were all probably around my dad's age but I felt like they might have a daughter and she might go through something like this and it's real. Whether it had been a woman or a younger guy who had a sister, I felt like they all looked at me as if to say 'This is real for you.'"

In my reading and working on the literature review I have come across many writings on the importance of patient compliance and taking an active role in managing their conditions in the context of chronic illness. I am prepared to argue, at this stage, that this orientation towards the person, by the willingness of the clinician to be seen as a whole themselves by bringing their whole human self into the encounter, is a powerful and empowering experience for the patient, who in turn, do seem more likely to follow the advice and become more active in their own care.

This was common across most (but not all) of the care experiences of the people with WPTA clinicians, but not unique to them. It is my analysis that it is more common, and more likely to happen with WPTA clinicians because of their own views of illness aetiology and mind-body connections and therefore leads to their own willingness to bring the whole of themselves to the encounter – while attending to professional boundaries, but not being restricted/captured by them.

On reflection, it appears that when the clinician is prepared to bring themselves as persons to the clinical encounter, the patient interprets that in many sophisticated ways, such as inviting them to bring their whole self into the encounter as well as the clinician being respectful of the patients' own expertise and resources in dealing with their own illness. This can be linked back to writing in the field of person-centred care regarding the importance of acknowledging the patient as experts in their own condition.

Another example is David, a man in his thirties seen in the immunology department in Auckland hospital for urticaria. He has experienced seeing councillors and psychotherapists in the past, and throughout his interview contrasted those experiences with the experience of the WPTA in the hospital.

“It was almost like we were peers in a way. Which is very important to me because often times I find that doctors think that because they are doctors they are so much better than other people and you know all that sense that we have all this knowledge. Well yes I have all this knowledge too just not medical related. You know I am not going to be; you know joke about it. So that was nice. Yeah I don't know, so it was more like peers talking, even though she is older than me. But you know there was a sense that we would share ideas. And it wasn't just me having to be receptive to this wisdom coming from above.”

David goes on to explain why this might be so important for him and how it relates to the positive outcomes in terms of his conditions:

“So I mean because there is often that idea that after there has been all this medication and there still hasn't been this affect the placebo, that some sort of placebo type thing would be beneficial and so this kind of respect, this sort of treating patients as peers and sharing and kind of that can make people feel confident and that would be a sort of placebo affect maybe?”

The two most vivid interviews that oriented me to go back to the data and explore boundaries, and the clinicians' own willingness to bring themselves into the encounter were from two people who were seen by a WPTA physiotherapist. Colleen is a woman in her forties who was born prematurely and diagnosed in very early childhood with a debilitating and incurable condition. She has had many, extremely traumatic operations as a child, which left her deeply affected. She went to see a physiotherapist to challenge her fear, as physiotherapy as a child meant pain: *“So the word physio, the word doctor, the word hospital, the idea of being touched or pushed or manipulated, the whole, there is a resistance to it, there is a stress around it and I wanted to try and engage. And I actually thought that (clinician) would be someone who could work with me in the way that I chose to work with aligns in my healing journey. And I would be bridging a little bit going back to the model that is physio.”*

She experienced many very boundaried encounters with medical clinicians and the extracts below speak to her own reflections on professional boundaries in the medical

encounter, and the impact they have had on her as a patient. The first extract is Colleen reflecting on the experience of meeting with the physiotherapist and the student working with her for the first or second time.

“And we were asked to do mindfulness walking and I couldn’t do it. I was asked, you know it was like being asked to leave a room where I felt safe and I realised as I stood outside I wasn’t allowed, I wasn’t allowed. The me wasn’t allowed. I was told that I couldn’t walk, that I wouldn’t be able to do this, that I wouldn’t be able to do that, that I needed to be fixed. The (names herself) the real me, the little me who didn’t see she had a problem at all was told that she couldn’t. And so I have a real stress about being allowed. I am almost too conscious of boundaries. And the feeling of someone else knowing even a little bit of the story and being willing to share it, like it was allowed that I could hear.”

I: What was allowed?

P: That I could hear part of (clinicians) story. That I could hear part of the student’s story. And that is not allowed in many professional practices, you have to keep your boundaries, you have to keep your space, you have to keep your stuff out of the room. Whereas this stuff was in the room and it was allowed and it was explored and it was negotiated around. Part of the difficulty I have with professional is that it is not real. In that moment there is a reality but it’s not real. It’s not two people sharing a story.”

As Colleen continually referred to the topic of boundaries, I wanted to explore that more with her and the full exchange below provoked my thinking more deeply which led to exploration of boundaries with Dan, the final participant.

“P: When I am not in that room I remember that feeling of being nurtured, of being heard, of being allowed in that freedom. I remember that even if I am not in a particular clinical session. I remember the feeling of how it felt to be touched, when I was touched. I remember the compassion, I remember the willingness to be real with me.

I: That’s brilliant. And where I want to test with you that sense of being with a professional, she is a professional.

P: She is.

I: Who was a physiotherapist who has some boundaries and yet what I am hearing is those boundaries are not rigid and fixed. Can you elaborate what did these experiences feel because you have that ability to think she is trained as a physiotherapist, she is in the medical profession and yet there are boundaries, I am hearing there are some boundaries in the room. Can you articulate what it is about the way the boundaries are and the professionalism is in that space that is different? That is enhanced?

P: I would like to say that it is a space created rather than boundaries. Because I am very conscious of the boundaries as you know I mentioned earlier I said my sister has done counselling and I talk to her when I can and she finds it interesting that I if you like have friendships with people who I have done counselling with or had sessions with. I mean I am conscious of boundaries so it’s me that has it in a sense and it is a surprise to find that something is ok. I think in her particular, my sisters form of counselling she trained in somatic psychotherapy, they talk about what’s in the room I suppose more openly in a sense where it is more acknowledged and I mention that

because that appeals to me. You know in that sense of connection it's also the space between it's not the overt, it's not the obvious, it's not even the voice or the way the room is laid out although that helps. It's the sense of being safe and with the Living Well Group that just finished yesterday I had a sense of being in a crucible that was also a cradle so it's a space where there is going to be change and I might be challenged. Had I continued working with (WPTA physiotherapist) I am reasonably certain that I would of said 'Can you figure out some exercises for me', I am not quite there yet, my body is not quite there yet but that is what I am aiming for when all of me is ready."

The last sentence is of particular importance and speaks to the willingness of a person like Colleen who has a deep mistrust of the medical system because of her history and experiences, to re-engage with mainstream treatment as a consequence of the WPTA experience.

In the interview with Colleen, towards the end, she described the WPTA physiotherapist as being able to 'see what is not seen and hear what is not heard', when I explored this further with her, she came back to the issue of boundaries, and how the physiotherapist was prepared to bring her whole self into the encounter which deeply resonated with her. I think that this extract clearly demonstrates how the patient is constantly observing and making their own judgements about whether they will 'allow' or 'give permission' for the clinician to see them.

"I: And what is it that enables her to do that? To see what is not seen and hear what is not heard?

P: Her faith. Her genuine love and appreciation of the human body and how it works. That is who she is as a physio. I haven't experienced much of the physio side of her but I can see. And her genuine love and caring for her fellow human beings. It goes deeper because she allows herself to be vulnerable, I think, if I may speak so freely. And it's an interesting position to hold I think because I think those clinical boundaries make it easier, even though you may not get the same results. There's a reason for it but I think she is a person first too. I think yeah person centred, if you can be person centred with me. If you can bring your person rather than your profession into the ring first."

In the last interview with Dan, a man who was referred to the physiotherapist by a psychologist he was seeing, because of depression, I was able to explore the notion of professional identities and boundaries further. Dan has identified (prior to seeing the WPTA physiotherapist) that he had deep issues with touch because of his childhood and the lack of touching in his home environment. The psychologist suggested he might benefit from working with the physiotherapist because of the touch aspect.

Dan was unique in that he has experienced a long-term therapeutic relationship with a psychologist who worked from schema perspective and is concurrently seeing a psychotherapist whom he is seeing twice a week. Throughout the interview he contrasted how he experienced the encounters with these clinicians.

I have chosen to include most of the extract from this last interview, with light editing, as Dan, with his experience was incredibly articulate in how he crystallised his own multi-layered experiences. The extract below follows an exchange where he told me how in his encounters with the WPTA physiotherapist he feels his high anxiety levels subside. I explored with him what he thought was contributing to it, and the following took place:

P: I think it's touch.

I: The touch?

P: Yeah. It's definitely that, yeah.

I: What is it about touch?

P: I think it's bridging that gap. So if I am talking to someone, a therapist, there is this gap and it feels like, and they also, it also feels like they are, there's boundaries obviously, there's boundaries. And they feel, they feel, well for me at least it's, and I definitely talked about this with them, it feels like a, it's a recurrence of childhood sort of rejection. It's rejection. That's how I interpret it, that's how it feels.

I: It's the psychology and the psychotherapy?

P: Yeah. It's sort of like 'Ok so I get to talk about it, but stay over there.' Yeah so there is this kind of like, whereas (clinician) it is like, there isn't that sort of, the boundaries are completely different.

I: And how are they different?

P: I think it's just the, I keep in my, to me it seems like she is just closer.

I: Because of the touch?

P: Yeah so the boundary is, you know I thought on the continuum you know she is further along, there's sort of, how close it's acceptable. And that's quite different to say a doctor who maybe actually physically touching you, but that's a completely different feeling.

I: Can you tell me about that?

*P: I just wonder if, **it's sort of like the difference of being looked at and being seen.** So that's one way I sort of think about it."*

At this point I explored with him what he meant, he found it hard to focus on the experience rather than his interpretation of the experience. Nonetheless, even though he focused on the touch element, the exchange below reveals something deeper about the willingness of the clinician to bring her own authentic self into the encounter:

"P: For me it's a, it's kind of like the direction of the, what it is, energy, let's just call it that for the moment. It's the direction. And it seems like being looked at is, it's all one direction, it's coming in, it's inwards and there's no, so and whereas with (clinician) she is receiving as well. So she is receiving, it's sort of counter to what you would think looking at. But seen seems to be sort of a 2-way thing where there is a (thinks), gee I have never really tried to explain it.

I: It's beautiful, you are doing great.

P: So I think it's this sort of, there is sort of a feedback loop that goes around, I am just trying to think. It's sort of like, there is this feeling, I will just give you another, there is something I have read it's called, someone has described it as feeling felt. That's another way, and I think that's somebody like Dan Zeag or somebody like that, talks about that. I guess it's seeing that there's empathy. It's feeling the connection coming back. I guess it's sort of the reflection thing but it goes in both directions and I think there is a certain amount of vulnerability on (clinician)s part. She is ok with that. So feel that she is not like blocking what's happening, what's coming from me. And it's sort of like accepting and saying 'Ok' and moving back and saying 'Well how's this?' So there is a real kind of flow of something."

Following this, I asked him to try and reflect on these encounters vis a vis his encounters with both the clinical psychologists and the psychotherapist:

"P: Yeah so I think the, I guess from, it feels like kind of, it does feel a little bit like talking to a wall sometimes. So there's things reflected back.

I: In psychotherapist? Or both?

P: Both I would say. I would say it's to different degrees. Now that's not to say that there isn't, it's just that I know they are reflecting things back. I know that that's kind of what they are doing but there is a, because there is necessary boundaries, they can't really, they are analysing. I guess that I can see their minds ticking over. You know I know that things are going over in their mind, yes ok, and I can see it happening because that's their job so they are analysing the whole time. Whereas it's not like a more natural or normal sort of relationship with somebody where it seems to be, it's more, with someone it can be more genuine or authentic. Whereas I think there is I think, even though they genuinely care there is a little bit of a, it's kind of a in some ways a fake relationship. It is easy to get drawn into it as a real relationship. It's very tempting but it's not.

I: And with (clinician)?

P: I think that she is just more sort of authentic."

In conclusion:

It was through including physiotherapists with their professional 'licence' to touch the person, which led to focusing and honing my gaze on this concept. What is interesting, is that in all of the interviews with people who saw physiotherapists, the core aspect of the experience was the verbal acknowledgment of the body in the encounter, through devices such as acknowledging and highlighting how the person moved, through breathing instructions and by allowing them time to 'arrive' in the room. None of which involved actual touch. Touch was involved in the encounter of course, but many commented how it was 'less than what they expected'. It is also important to reflect that medical doctors and nurses are also 'licensed' to touch, and that touch if done carelessly, as in Colleen's interview, can in fact harm the person they are attempting to treat.

I am inclined to suggest, following the analysis of all of the interviews that it is in fact the ways by which the different professions construct their own professional identities which is of greater importance in this discussion (than the discussion of the importance of license to touch or not). This is not specific to medical doctors, psychotherapists and clinical psychologists, but includes them all as well as others like other physiotherapists. *It is more to do with the willingness of the clinician to bring their whole self, including but not limited to, their professional identity into the encounter.* This analysis does not discount the importance of professionalism and professional identities. All of the people with whom I explored the importance of professional identity felt that this was key to their willingness to engage in the therapeutic relationship.

This analysis highlights the importance of reflecting on the ways by which the professionals orient themselves towards their professional identity which has a powerful impact on the individual being treated. It forces a reflection on the ways by which professional health clinicians construct their identity. Is this something they use to hide behind, constructing high walls from which they *look at* the person in front of them? Or is it that they use their professional identities to ground them, constructing flexible and constantly negotiated boundaries, which enables them *to see* the person in front of them.

Analytical memo (Wednesday, 2 November 2016)

My thoughts about the 'story' in the WPTA therapeutic experience from the perspective of the people being treated.

Throughout the analysis I used the 'story' aspect of the WPTA as a sensitising concept given the central role the story plays in the writing of Doctor Broom as well as in his questioning of my analysis given his role as a thoughtful clinician (Bowen, 2006) as my own assumptions about my own progress.

A specific life story and how it is linked to a condition is very vividly presented in Dr Broom's writing, and was evident in the videos analysed in the secondary analysis phase of this research. The videos were well packaged in a sense that the filmmaker did a lot of pre-work with the interviewees (which was evident in the raw extracts) for them to tell their illness and healing story in a way that highlighted the link with their personal/historical/psychological story.

However, in the interviews done as part of the previous research in the immunology clinic and in my own interviews, which were very 'raw', in that no preparation or rehearsal took place, the people interviewed talked very little about a specific story which they have come to see as central to their illness. They have told many stories, most of which related to their 'health story' of suffering and living a symptom entangled life, in which the WPTA has offered them a way to see the condition differently and develop an understanding of how the body and the mind are connected, giving the freedom for them to be able to move on from living a symptom entangled life.

In reflecting and engaging with the data with respect to understanding the role of the 'story' in the WPTA experience and how that might be of general relevance to improving mainstream care for people with chronic conditions, I have come to the following observations:

- It isn't clear what constitutes a 'story' in this context, and that there is a possible danger in ascribing hierarchies to what constitutes a story and what doesn't.
- Clinicians who focus on wanting to hear a specific life story which can explain the condition (be it in a metaphoric sense or not), can be experienced as reductionist and threatening. And in some cases, the person being treated may feel like a disappointment to the clinician when there is no such story.
- Focusing on a story may contribute to an ongoing dualistic experience and interpretation of their condition.
- What all the people being treated take for themselves, irrespective of whether there is a story or not, is the understanding of the mind body links and how that can help them, in very practical ways, manage their condition – which speaks to my original theme from the secondary analysis which prevailed throughout and I labelled as **'a door into understanding'** or **'connecting the dots'**. Both of these are direct quotes and connecting the dots was a phrase used throughout my interviews by multiple people who were seen by different clinicians.

What is a story?

My own reading of the data and my reflection on the listening component of the encounters has resulted in the three and then four themes that attend to the listening component – **'the heart of listening'** theme is my attempt to address this, which speaks

to the experience of the story the person wanted to tell being listened to. People can sense if the clinician is truly open to hear the story they want to tell.

Indeed Beth has come to understand her illness in the context of the abuse – her understanding relates to how the asthma became a way for herself to remove herself from the abuse – and later on other stressful situations. The extract below is in direct response to my asking her to describe the first encounter with the WPTA hospital clinician (this is an unedited continuous extract):

“And so she asked me when I started getting asthma, and I thought ok that’s ok I can answer that so I said ‘puberty.’ And then she said ‘Ok, I want you to think back and tell me what crisis or what trauma happened to you when that started, at that age?’ And I thought ‘Holy my goodness’ and at that age (a family member) started abusing me. And so I remember sitting there and she was a bit weepy and my husband was weepy and I just looked at her and said ‘Look in future you should tell people you are going straight for the jugular not just do it!’ For me it’s just part of my life so you know it’s my story but it’s you know.

So we then started investigating that and we then investigated other issues too that might in some ways be not necessarily triggers but might (sighs) exacerbate things. I have a very stressful, no I had a very stressful mother-daughter relationship. Since seeing (hospital WPTA clinician) and a counsellor as well I have realised that the only way I am going to have a positive relationship with my mother is if I change. She will never change, she is set in her ways, she will never change. And so (WPTA hospital clinician) brought me to that sort of understanding that in counselling it sort of reinforced it and I understood it a bit better. So that was a great help. We kept talking a little bit more and I told him that 1977 my stepfather started abusing me too. And some days I’d have them one after the other abuse me. And so we spent a lot of time talking about how the fact that when life got hard because I couldn’t in my mind do anything to work it out and help it I had an asthma attack which avoided the whole issue and took all the attention off what was happening and there was the asthma and everything was fine and everyone was ‘Oh poor (names herself) she’s got asthma.’ And it made it, and so we spent more time investigating that, which sometimes were easier than others.”

Beth’s story is incredibly powerful, but I am acknowledging the analytical risk highlighted by Thorne and others of such powerful stories ‘hijacking’ the analytical process. **When the story is present it is a powerful illustration.** However, in more of my interviews, there wasn’t such a powerful story – and yet the experience was still healing and effective, and for most of them seem to result in alleviating their chronic symptoms.

Moreover, Beth herself talks of the powerful connection made in that first encounter as quite traumatic – and she speaks to it later on in the interview. In itself this needs attending to, the emotional impact on the person being treated from the connection being made for them. The implication for practice being the possible need for greater care and attendance for the introduction of such connections, and how the clinician, through bringing their whole self (see earlier memo) can ‘soften’ this experience for the person they are treating.

In some cases, there were many stories, and from the clinical encounter, the participants, though their new understanding of the mind-body links from the

therapeutic encounters (the theme of a door into understanding and connecting the dots) came to explain to themselves their illness or previous conditions in the context of their lives which gave them a sense of growth and freedom.

David, for example, the man in his thirties suffering from urticaria, towards the end of our interview shares with me how he has now come to see his childhood sinusitis as a way of delaying being sent to boarding school:

“P: Yeah I mean I guess like from, like for me the hives isn’t just an isolated thing, so it generated other allergic reactions I had.

I: Tell me.

P: So for example when I was a teenager I used to go to boarding school and it was maybe like 10 hours’ drive away.... Yeah. Because we lived in like the North West part of the country and there was like no schools so I had to go to school in (names a town). And I hated boarding school, it was like the worst thing in my life. Because it’s not a place for anybody with any sort of sensitive leanings, do you know what I mean? Like anyone who likes reading or anybody who is not part of a herd. And I used to, so I would go home from the holidays and the last 2 days of the holidays I would always get incredible sort of hay fever and I would be like sneezing and crying and my face would get puffy and I would have, I guess there would be some hives but I can’t really remember the hives but it was always like uncontrollable and my nose would just keep pouring. And they would just be like ‘Oh it’s just psychosomatic, just get over it, and go to school.’

So if somebody had taken the time to be a little bit more you know, ‘The reason why you are doing this is because of this and we should try and figure out why you feel this way about boarding school and are there any other alternatives?’ So that would of, I would of not of had that. Because I was very prone to sinusitis as well and so I had like these massive headaches all the time, and that was probably related to the stress of being at boarding school.

*So I would go to ENT specialists and they would stick the vacuum cleaner at the back of, and they would just drain out the mucus but there was never any sort of, what was the underlying, it was just treat the symptom. So you know I feel like I have had a lot of similar stress related things over my life that nobody has actually ever taken the time to be like ‘Ok well what is it?’ It’s always just ‘Ok let’s just treat the symptom’ and then over time the symptom either changes or it gets better. **But no one has ever really taken the time to ever explain it to me.**”*

The potential shortcoming/dangers of being overly focused on finding a story.

As I kept interrogating the data through reading and listening, I came to see that the WPTA orientation or even bias towards the ‘story’ was, in some cases, experienced as a reductionist and unsatisfactory experience by the person being treated. Those people who were more ‘open’ to the possibility of the emotional story being connected with their condition, like Valery above, found the experience of the story link powerful, but for others, this was at times, traumatic and deeply unsatisfactory such as in Jason’s case.

In another interview, where the WPTA hospital clinician had established a very warm and trusting relationship with the person, Lorie, a woman in her fifties who has an autoimmune condition, articulated that very well: *“She (WPTA clinician) would tell me many stories of patients who, ... came to see her, told her the story, figured out what*

was triggering it, went 'Oh' and then didn't get the disease anymore. And eventually after ... said to (WPTA hospital clinician) 'We haven't had that moment.' You know like when we get to a point and I say 'Ok that's the trigger' and I stop getting the disease."

This quote highlights a possible additional risk, that even for those who are willing/open/ready to explore these connections between their life experiences and their condition, if there isn't that clear link as powerfully illustrated in Beth's story above, this may be experienced as a sense of failure on part of the patient for not having this explanatory story.

Certainly, the willingness of the clinician to take into account every part of the person's life as it may pertain to their conditions is a crucial element of the WPTA. Notwithstanding that, my construction of the interviews illustrates the possible powerful pitfalls of being overly story oriented, as opposed to being wholly person oriented, which might mean attending to other, more mundane or mechanical stories.

People ending up with a dualistic understanding of their condition from the WPTA experience.

Interestingly, in some cases when people saw a psychotherapist as well as a WPTA clinician, they spoke of their condition and the experience in very dualistic terms. Ian a man in his sixties who is being seen in the immunology department for an autoimmune condition, has been seeing a WPTA clinician in the hospital, as well as WPTA psychotherapist whom he was referred to, over a substantial period of time. Ian feels very positively about his experiences both in the hospital and with the psychotherapist. Throughout his interview, he kept referring to the 'mind' side, and the 'body' side as illustrated in the extract below:

"But in the beginning all I could think about was my disease. All the reading I did was on the different (names his autoimmune condition) and things like that. And I was totally immersed in the body side of it. Now I don't even think about the disease anymore I am totally immersed in my emotional side and in developing myself as a person. So it's gone from the body side completely to the mind side. And I've sort of got to the stage now where I believe that having my life organised and being happy as a person and just by living my life the way I would like to live it I find that I am content, I am relaxed, I don't have stress in my life and those things I now believe are as important as the medical side. And I am hoping that at one stage that will influence the disease that I have. And whether it does or it doesn't, I don't know."

Jason from the example above was also referred to WPTA psychotherapist. He described that relationship with the WPTA psychotherapist very favourably and found the experience very helpful. His description of the experience is quite dualistic in similar ways to Ian's:

"Well just before it was like I gave up. It was like, but now I want to. If I had the money I would still be going to see (WPTA psychotherapist) because I was making traction, I was getting somewhere. And I honestly, because I just got a promotion at work and I don't believe I would of gotten there if it wasn't for that work that I did with the, it wasn't just about the getting better from the urticaria. She has always made it as the work that we did here was just to better myself and if it was a result that my urticaria would go away, if it was my mind telling my body, if it was a result that it would go away then I was happy. But then it turned, I wasn't really bothered by that anymore I

was more wanting to get better mentally. And then I was able to see things better, not see things better but I was able to deal with things better than I would normally. Yeah because I was really, if there was any problems, if there was any issues just kind of harden up, get over it. But talking to you it's I know that's not always the right way."

It seems that what the people interviewed took from the WPTA psychotherapeutic experience was centred around different ways for coping with their illness. However, their understanding of their illness did still seem to remain quite dualistic. What is very interesting to me is that those who may not have seen psychotherapists as well, be them people seen in the immunology clinic or by physiotherapists seemed in their interviews to have come to see their condition in much more integrated and less dualistic ways.

The door into understanding remains the most powerful thing people articulate as taking away from all of the WPTA experiences.

For all the people I interviewed, it was the practical ways by which they came to view their condition, through understanding the mind-body connections which they spoke of as being most beneficial for them. They experienced the ways by which clinicians **'connected the dots'** or **'opened doors into understanding'** for them as profound and freeing.

For example, Lorie from the example above reflected deeply on how she benefited from understanding the connections. Her interview spoke to both the interpersonal elements of listening in the therapeutic experience as well as the content she became educated in – of understanding the connections. She related that to how she now interprets these connections and applies them to her own management of her conditions:

"When I eventually gently accepted the fact that my mind and my body are connected, they talk to each other in their mind-body talk. With messages, hormonal messages or interactions or whatever it is, nerve impulses or. When I gently accepted that that actually happened and that could contribute to disease I became hopeful. I became hopeful that the conditions could then change if I unlocked the negativity or if I unlocked the secret of that conversation, I think that's really it. If I unlocked the secret of the conversation which I couldn't hear with my mind. So I lived a lot in my mind, and I couldn't hear the message. But when I understood that there was a message, there were messages going from my mind to my body and that, that undoubtedly was contributing to my illnesses then I could reflect when I started getting symptoms I could reflect on what I had been thinking about and what situations were causing stress."

Beth as well, spoke about how that enhanced understanding of the 'role' of asthma in her life has resulted in her behaving in different ways and removing herself from emotionally laden situations with family members which in turn resulted in her not having been hospitalised for three years. Prior to seeing the hospital WPTA she was hospitalised monthly for severe asthma attacks. *"And so it doesn't matter whether it is (names family members), in some ways anyone now who causes great aggravation or (sighs) I can see is bringing me into a tense place where I think 'This is dangerous for my health, this is the scenario I could get an asthma attack in. I can see that there's, that this is dangerous that the stress is getting to high that my body is going to do it's out.' And so I just remove myself from it or something like that."*

It is my reflection on the data, that in some cases the 'story' offered a powerful entry for the clinician for the whole of the person. However from the patient's perspective this

isn't the only or most effective way of doing so. From the patient's perspective it is the willingness of the clinician to bring their own, whole self into the encounter for them to feel seen, which appears to be a necessary element in a powerful WPTA experience. The clinician's attendance to the story doesn't seem to have the same resonance from the perspective of the person being treated.

Memo 3– first encounters and negotiating the therapeutic relationship
Monday, 14 November 2016

This memo is intended as a vehicle in aiding me to process and integrate the threads which I term in previous memos as the importance of clinicians bringing the whole of themselves into the clinical encounter, and the significance of the ‘story’ in the WPTA relationship. Throughout the analysis I used the ‘story’ aspect of the WPTA as a sensitising concept given the central role the story plays in the writing of Doctor Broom as well as in his questioning of my analysis given his role as a thoughtful clinician (Bowen, 2006). In reflecting on these topics I thought that focusing on isolating the first encounters where these were available, might be of value in helping me deepen my understanding.

In undertaking this analysis I critically interrogated these descriptions with three key questions in mind:

1. What happens in that first encounter that shapes the clinical relationship?
2. What is the role of ‘readiness’ in these first encounters?
3. What is the person’s view of the centrality of the story in their own illness experience and how does this awareness shape how they come to see their condition?

As part of the analysis I deeply reflected on Beth’s story. Beth is a woman in her fifties who suffered sexual abuse in her adolescent years and has been referred for severe allergies and asthma. Beth’s story was revealed in the first encounter, where the WPTA hospital clinician illustrated the link for her by highlighting the onset of the asthma at the same time as the abuse (see ‘story’ memo). Beth’s was the only interview, in which the participant relayed a specific and vivid story, and in her interview that story was revealed in the first encounter.

In summary:

Through using the story as a sensitising concept in analysing Beth’s and others’ interviews, I was able to finely tune my understanding of the role the story may play in the WPTA therapeutic relationship. I came to understand that stories could be very powerful for the person *if first, there is a negotiated understanding* between the clinician and the patient about the mind and body links, and this negotiations success is dependent on the quality of therapeutic relationship. In therapeutic relationship, I refer specifically to the clinician’s ability to bring themselves into the encounter and their willingness to listen to the story the person wants to tell. I suggest that it is problematic to address the centrality of the story in the WPTA clinical encounter in isolation from this negotiation. Further, the analysis suggests that the extent to which the therapeutic relationship established between the person and the clinician *is integral* to the patient’s willingness to engage in the WPTA experience.

On readiness:

My other sensitising concept (from my assumptions in the beginning of this process) I used in analysing these first encounters was that of the person’s own readiness to engage in the WPTA clinical encounter. My understanding of readiness, was the extent to which the person was willing to engage in the psychotherapeutic/psychological aspects of the WPTA, that is, discussing highly personal experiences. Through this

phase of the analysis, I came to view readiness as something that has to be negotiated between the clinician and the person, before other more intimate aspects of the person's life can be examined in this context. The interviews revealed that the success of this negotiation is dependent on the willingness of the clinician to bring more of their whole self into the clinical encounter (see earlier memo).

First encounters seriously matter:

During the first encounters is where the person assesses whether it is safe for them to bring the whole of themselves, including their story, to the clinical space, and whether they are going to engage in the therapeutic relationships. I tried to understand the mechanisms that facilitate this by unpacking the concept of listening in my analysis. Participants spent a lot of time during interviews articulating the importance of these negotiations, and the 'cues' they were attending to in deciding whether or not to engage.

It wasn't the content of what the clinicians were saying or asking, but the ways they interacted with the participants in that first encounter – and sometimes in subsequent ones, which lay the ground for the participants to decide to engage in the relationship. My attempt at constructing a theme around this is *the heart of listening* – listening to the story the person wants to bring across.

In a study of helpful and unhelpful communication with people who suffer from cancer, (Thorne et al., 2005), the authors came to understand the centrality of the human connection that the participants experience as 'being known', as an experience of being acknowledged as a person in the inherently difficult context of living with cancer. This study has strong parallels to my analysis. This concept of being known certainly is evident in these interviews, and can be seen in the need of participants for clinicians to acknowledge their physical suffering as well as their history or stories.

One participant, suffering from unexplained, severe and painful abdominal pain attacks who was seeing a WPTA physiotherapist articulated this in her interview "*She (WPTA physiotherapist) was very clear that 'Look if it is anxiety that is the root of this or it is like your past that is the root of this that doesn't make it any less real you are still feeling this pain and it's still absolutely valid.' And it did kind of, it was so good to hear someone finally say that without being like 'This isn't real.'*" Indeed (Thorne et al., 2005) specifically comment on the powerful impact of clinicians explicitly acknowledging the suffering and inherently horrible experience of having cancer.

In the interviews, clinicians who adapted their orientation to the person in front of them, were experienced as healing. For example, Jason, a man in his twenties with hives, experienced his GP as attending to him fully as he took the time to explain how things were connected: "*That comes back to (names doctor/GP) he has the only doctor that really listened to me. And even if I was wrong he would always, he was able to talk me through it. And in my mind that always kind of reassured me.*" Because Jason felt safe with this doctor, he was willing to engage fully with him, following his advice and course of treatments. In contrast, Jason experienced his first and subsequent encounters with the hospital WPTA as very problematic when she raised with him the possibility of mind-body connection, because she didn't take the time to negotiate an understanding of those links with him, didn't take the time to listen to the story he wanted to tell (one of physical symptoms and suffering) and as a consequence he experienced her as 'not listening': "*But when I explained, or when I tried to explain I was cut halfway through and told 'No this is what is happening and this is what you need to do.' So when I*

walked out of the room I was kind of like ‘Oh I still feel what I am trying to say, I haven’t been able to get it all out, I haven’t been able to say’ it was kind of like I don’t know what’s the word? Kind of like going to the shop and wanting to buy a Big Mac but walking out with an ice cream instead and that’s not what I hoped to get out of it.”

That negotiation may be interpreted by the person receiving the care as an attempt by the clinician to individualise their approach to the person in front of them. Patients make this assessment by critically responding to what the clinician is listening to, and the respect they have for the patient’s own understanding of their condition. Indeed (Thorne et al., 2005) in their discussion of their findings, suggest the patients or persons can “discern the difference between that which is standardized and that which ‘feels’ individualized.” (p. 895)

Entertaining the possibility of the specific story illness connection is scary: “***because you don’t really know what you are going to uncover when you start a process like this***”

Another way to underscore the importance of these negotiations in the first encounter is by comprehending quite how viscerally scary and threatening the experience of understanding the impact of *their own specific life story on their illness* can be for a person with an already debilitating chronic illness. Through the analytic process, I have come to comprehend the importance of acknowledging how destabilising this experience can be for the person, irrespective of their levels of ‘readiness’.

This was especially vivid in Valery’s interview who described how ‘open’ she is to the ways of understanding health and well being, but despite that, and her finding the clinician safe and encouraging, this is how she described her experience of comprehending the possibility of exploring the specific relationships in her life and how they might be related to her condition: “When you are sharing things about your childhood and emotions that make you cry with somebody else, it’s quite scary. I didn’t really think I was going to go into a physio’s office and have a boo hoo. Do you know, so yeah it’s scary ***because you don’t really know what you are going to uncover when you start a process like this.***”

Valerie’s way of articulating the experience as ‘scary’ was particularly notable because she described the interaction as very gentle, where the clinician took every step to work with her and alongside her: “It’s huge I mean you don’t go to a physio and talk about your relationship with your (names family members) and the linkage is that she is making, and we are together, ***it’s not just her, she’s not feeding it to me a slight little lightbulb is going off in my head like ‘Oh my gosh I never thought of it like that’***”.

The interpersonal aspect of the relationships appears crucial to the therapeutic component of the healing relationship. My analysis suggests that this negotiation to ‘enter the story aspect’ can be achieved successfully through the WPTA clinicians listening to the stories the person wants to tell, bringing the whole of themselves into the encounter, and educating their patients about the mind-body connections. This ‘education’ component seems to be successful when the clinicians use whatever makes sense to the person in front of them, be it psychotherapeutic, spiritual, or scientific pathways. Or by focusing on the experiential pathway through teaching breathing techniques. Adapting to what the person requires in negotiations, is part of a true person centred approach, and indeed a way for the person to discern that indeed this approach is individualised for them.

It appears that only once this negotiation is successful, the story component could be effectively brought into the relationship, however, in some cases it might not even be necessary. Some very experienced clinicians are incredibly skilled, who may be able to do it in the first encounter – but even then, as in Beth’s interview she recalls telling the experienced clinician *“Look in future you should tell people you are going straight for the jugular not just do it!”*

Where should clinicians place their gaze? Addressing the PhD question aspect of ‘general relevance of the WPTA to mainstream treatment of chronic conditions’

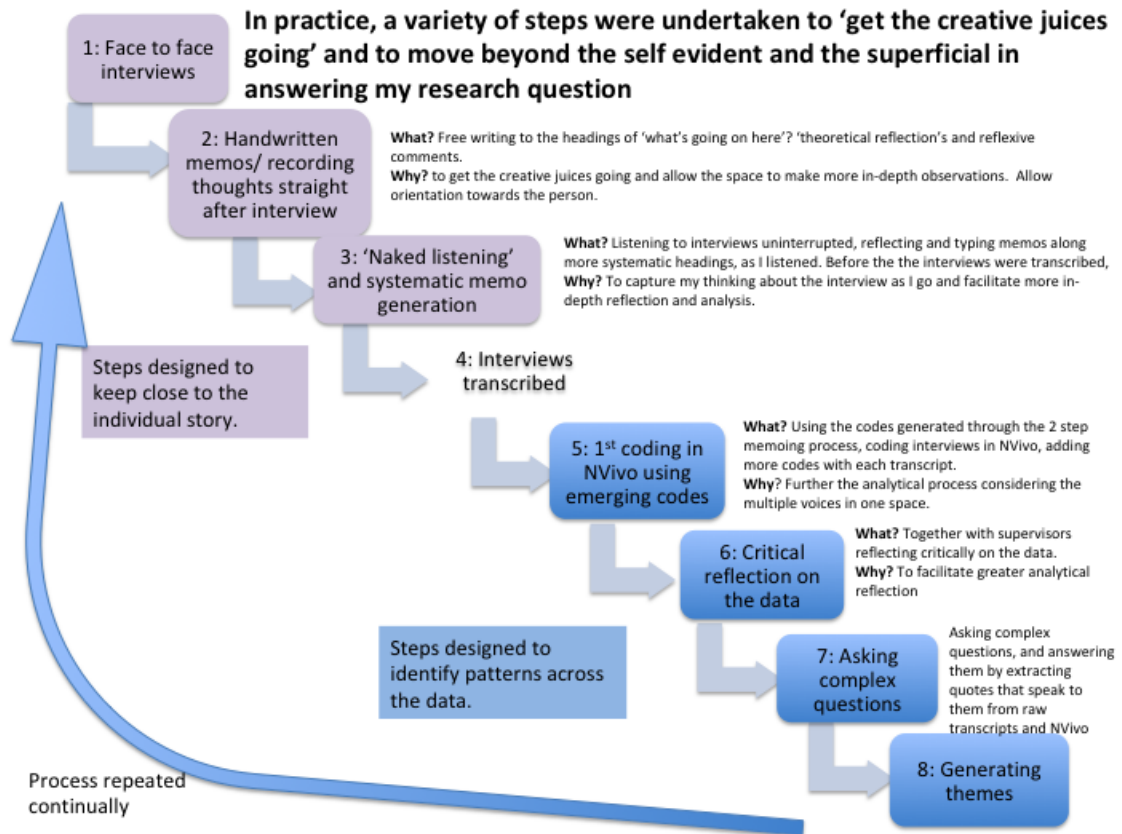
My analysis to date has highlighted the active and agentic role persons/patients take in assessing the ways by which clinicians negotiate the therapeutic relationships with them in all contexts. A premature focus on the *content* of the relationships or the story element of WPTA, can be experienced as reductionist by the person being treated, if this negotiation doesn’t take place successfully. Even if it does take place, and the person is ‘ready’ it is still experienced as ‘scary’ which could lead to a need to re-negotiate and tread very carefully.

Of particular importance is that many people benefited from understanding the connections between their psychological states, their history, their ‘mind’ and their physical conditioning *in abstract* of any particular personal story in the clinical encounter. Some related those understandings later on, in private, to their physical conditions. In those interviews, the therapeutic experience was still extremely beneficial to them and led in most case to significant reduction in their symptoms from their point of view.

The question then is, where should the therapeutic gaze be, on the story, or on the quality of negotiation process? In this stage of analysis I am inclined to suggest that patients experience positive outcomes when the gaze is firmly placed on negotiating the interpersonal therapeutic relationships. And that the story aspect may come later on, but not in all cases and the clinician would benefit from being thoughtful and careful with it.

Indeed Valery when asked about what can other clinicians learn from the physiotherapist she was working with, answered: *“It is challenging because there is no formula here and it takes more skill and experience to do this and that’s why it is harder because you can’t, you know it’s like the difference between someone who is paint by numbers and an artist. It’s a combination of those skills so that’s challenging.”*

Appendix S: Detailed and sequential account of the analytical process with illustrative examples



During the analytical process of the first ten interviews, preliminary codes were continually (during the coding of each subsequent interview) generated in NVivo to help make sense of the data;

- Self insight
- Control
- Emotional discomfort
- Empowerment
- Helpful not helpful communication
- Importance of professional expertise
- Linking everything together
- Listening not listening
- Person centred experience in care and communication
- Self generated somatic metaphors
- Works for me but doesn't work for everybody.
- Psychotherapy as really helpful in the context of living with chronic illness
- Participating because wanting to give back
- Readiness
- The clinician as an educator, demystifying the condition/ the reactions and the impact it has for patients.
- Trust
- Illness experience
- Resistance
- Culture and ethnicity
- Food narratives
- Health system change
- Getting to the bottom of this
- A bit of a chaotic journey
- Being held
- Patients as experts in their illness and the health system.

Next, increasingly more complex questions were asked of the data around key concepts, and extracts were identified to help answer those; (part 1)

Suffering:

- What are the ways they describe their own suffering?
- In what ways has the medical system increased their suffering?
- What are the ways in which communications/relationships with medical professionals added to their suffering?

Relieving suffering:

- What are the ways relationships with other health providers relieved their suffering?
- What are the ways they describe how their suffering was relieved through receiving the WPTA? Do they go beyond the ways described above?
- What does it look like to 'not be suffering' to this person?

Readiness:

- Do they think readiness is needed for the approach to work?
- What does readiness (or not) look like for this person?
- Are there ways the clinician helped them become 'ready'? or ways they think clinicians can help 'resisting' patients become ready?
- Is there an impact of others (health professionals or friends and family) on readiness?

Professional identities:

- What role does the clinician's professional identity play in the experience of care?
- Is it important in the context of WPTA?

Next, increasingly more complex questions were asked of the data around key concepts and extracts were identified to help answer those; (part 2)

Listening:

- What is it that the clinician is listening to, which is helpful? (speak to content and/or intent)
- Is it important from the patient perspective what the clinician is listening to?
- What made the listening relevant and crucial in some way?

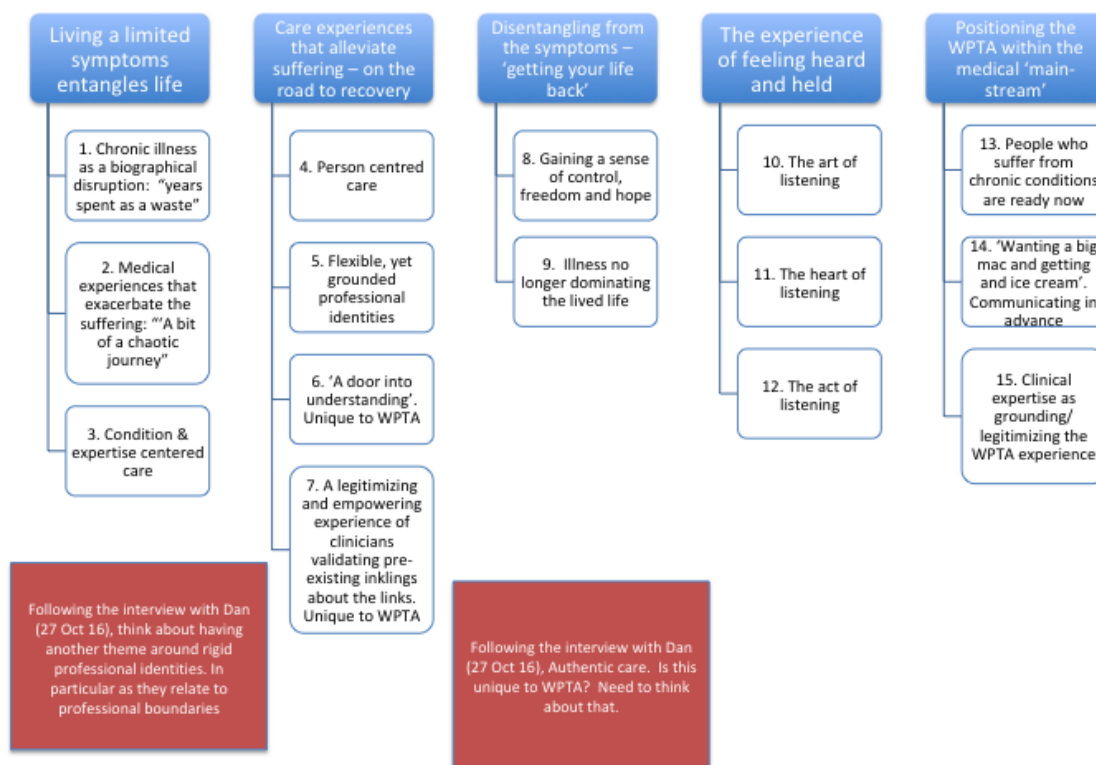
Being treated as persons:

- What is it about the content of the interaction that speaks to that?
- What is it that people speak to which illustrates that?
- What is it in the manner that speaks to that?
- Is it (the clinician's person centred orientation) sufficient in itself to relieve the suffering? Or is something else needed?

WPTA generally

- What are the things that resonates the most for people from the experience?
- Other quotes which speak to the experience which don't 'fit' in any of the questions above?
- Do they speak of their own 'sense making' of their illness in the context of their illness?
- Are there dangers/ specific areas of difficulty associated with the WPTA?

From the extracts, five overarching organising concepts and 15 themes were constructed to best answer the research question based on the first ten interviews (with people who saw the WPTA in the immunology clinic)



Concept: living a limited and illness entangled life

What is it?

Chronic illness as a biographical disruption:

Participants experience a significant biographical disruption journeying in and out of the medical system, a barrage of tests and probes, multiple interactions with medical professionals. In those with more severe symptoms the chronic illness appears as if it becomes the core of their sense of self – the 'thing' that defined them in how they saw themselves and related to others.

A bit of a 'Chaotic Journey' (Claire):

Refers to the patients' experience within the health system specifically. A sense of feeling lost, being handled like a 'product' moving through the 'production line'. Having to have multiple tests, numerous investigations and hospitalisation. These interactions add to the suffering and the sense of a biographical disruption.

Condition & expertise centred care: This theme refers to the sense of rigidness of many medical people the patients interacted with. Professional who are 'stuck' in their own professional identity and speak to patients in overly jargon manner, focusing on those symptoms, which fall under their own expertise.

What it 'looks like'?

- "So I had [diagnosed condition] right up to the age of probably puberty. Yeah up until around I was maybe 15, 16. And that was like I would get hospitalised for it, have really bad infections. Hospitalised for a couple of months, few months...Throughout my life yeah. Because I also had very [another diagnosed condition] too and I got hospitalised quite a lot for that too...." (Ben)

- "And I got shifted around practitioners and doctors and if it didn't fit into their box I got moved onto the next person who didn't take into consideration what had happened in the previous place and I just felt lost in the system and it totally affected my life last year to the point that I took 2 months off to just, not because the condition was so severe that it made me sick it was the stress around the condition and I needed to take time off to push for some answers or some help properly" (Amy)

- "They are throwing at us all this medical jargon, just stop and just think not everyone can understand what's going on....Approach us like we are not product, we are not just a file on your desk, next, next, next. Which I felt with some of the doctors I saw. I felt like I was just being pushed through, "hurry up, I want to go home" sort of thing, for them." (Claire)
- "but up until then I had been very much hitting these like small reductionist boxes that I wasn't fitting into. And I still don't fit into any of their boxes." (Amy)

Concept: Care experiences that alleviate suffering – on the road to recovery

(1)

What is it?

What it 'looks like'?

Person centred care: Participants were sophisticated in their interpretation of the interactions as a consequence of their own 'chaotic journeys'. They were aware if the clinicians are adopting themselves to the person in front of them in their manner and communication. This is experienced as a humanising experience.

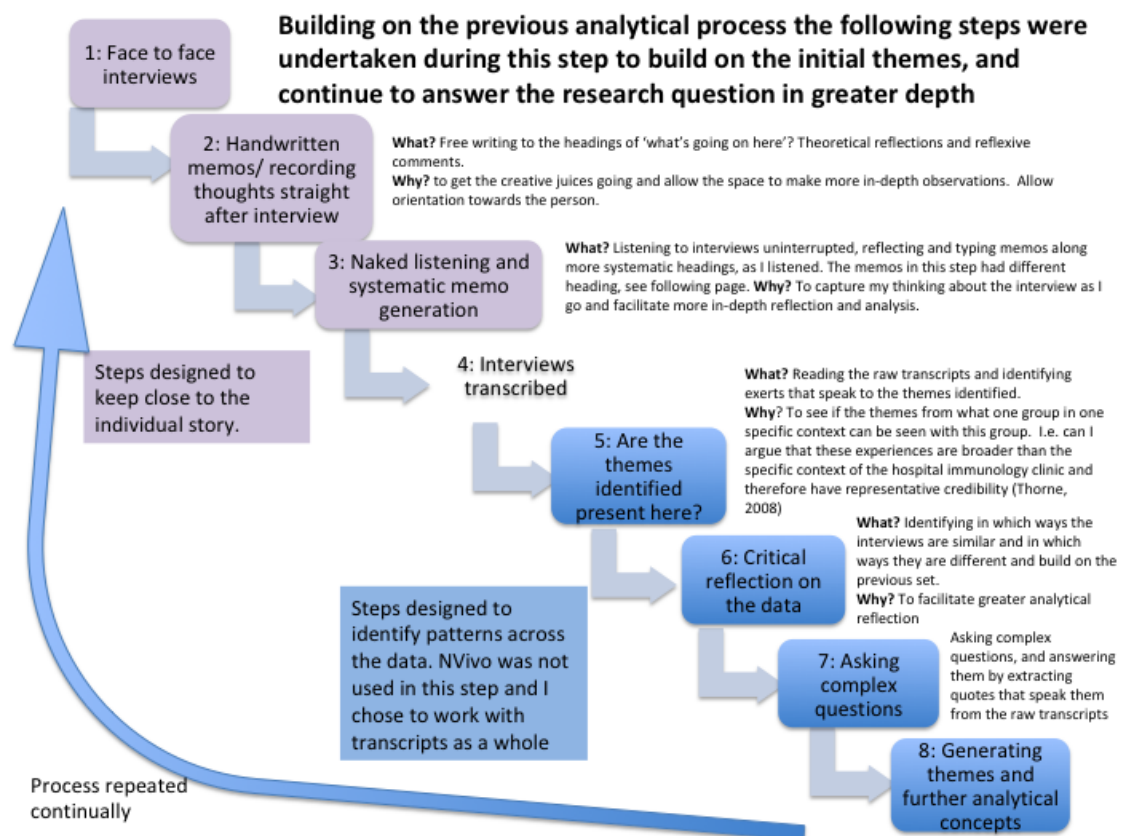
• "So just, (hospital WPTA) didn't look at her watch or anything, I don't even know if she was wearing one, but she didn't look at the time, she was comfortable in her mannerisms, she talked to us like we weren't just product like we were people, us being my mum & I and she didn't talk to us like we were other doctors. She talked to us so that we could understand, not saying that we are dumb but we don't understand what certain terminology means (laughs). She was good, she was really good." (Claire)

Flexible yet grounded professional identities: Clinicians who show willingness to try different things which might help the person – even if they fall 'outside' their prescribed professional identity. By doing so they demonstrate their genuine care for the person. They also show humility by admitting what they don't know.

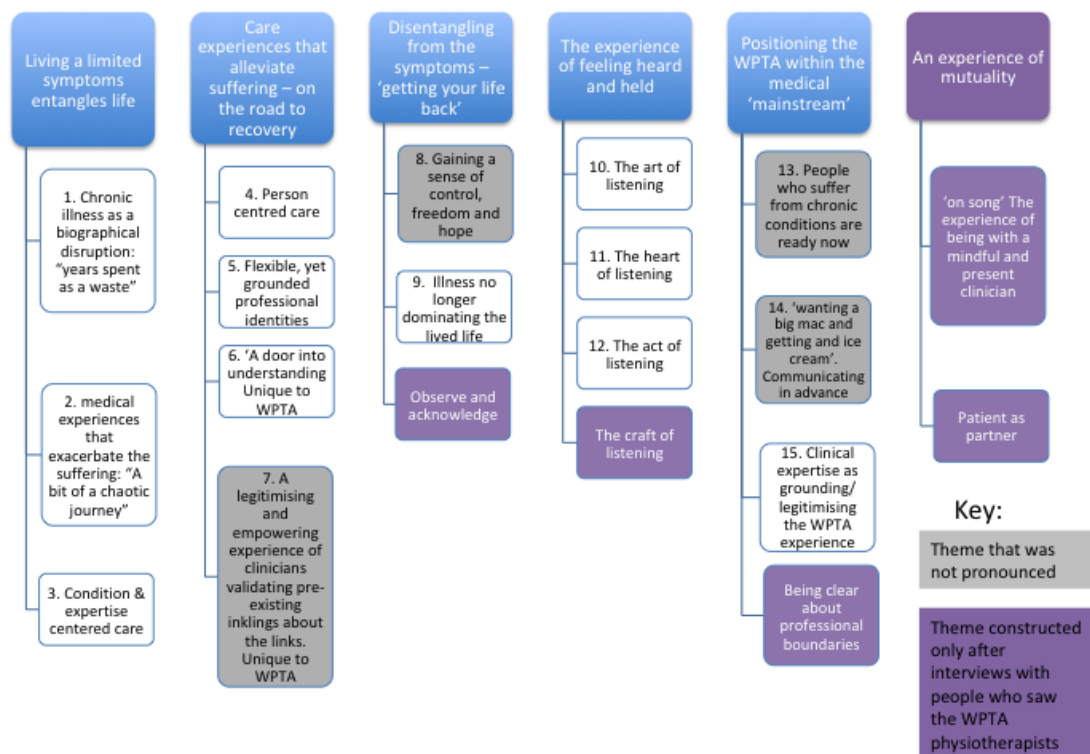
• "I think if I compare to the 4 main people who I think of the most thorough this experience is from (Hospital WPTA) approach compared to say like the good (one type of specialist) and the good (other type of specialist) who I feel were as much as they were in their field and specialists they still kind of had that open mind that "I have never heard of this before" they were honest. They were honest at their lack of ability to figure it out for me. And that they would help me as much as they can, they reassured me that they would make sure someone was looking after me and if they can't find it don't stop looking, there's more people out there, there's more options even if you go outside of the mainstream medical or, just that reassurance that they will do what they can to help me and test all they can in that sense." (Amy)

Interviews with people who saw WPTA physiotherapists

- It was decided that people who saw WPTA physiotherapists will be interviewed in order to explore how the WPTA approach is perceived by people who are treated by 'body' clinicians, That is, clinicians who incorporate touching as part of their therapeutic professional practice.
- Two physiotherapists were chosen as they were nominated as 'master' WPTA clinicians in their field by the WPTA experts.
- Five people who saw these physiotherapists were interviewed using a semi-structured interview guide. It is planned to interview five more.



The figure below demonstrates how my understanding of the organizing concepts and associated themes shifted as a consequence of this analytical step.



For the concept of disentangling from the symptoms, the theme of 'getting your life back' gaining a sense of control freedom and hope was less prevalent in the interviews. However, the shift in clinical focus to observing and acknowledging was very pronounced.

Illness no longer dominating the lived life: The therapeutic focus was more about coping and managing the symptoms – not about the person becoming symptom free.

- "The main thing that I think that I gained is that beforehand I just felt so powerless and I had no way of coping besides pain medication and I just felt, you know I was definitely starting to doubt myself as well like, you know because there had been months and there was no diagnosis I just felt "oh my god what if it is all me? What if you know I am wasting everyone's time and there is no cause?" I just felt so you know like powerless and so afraid that and I was second guessing everything. And when she said "look a) here are these ways of coping with it which are practically really really useful and I use them all the time." (Pauline)

Observe and acknowledge: The focus of the care experience on observing and acknowledging what is happening, not 'forcing' a resolution. An absence of any judgment. They did not feel 'judged' for not being able to cure themselves (this was present in some of the earlier interviews). There was a palpable sense of relief by interviewees about this shift in the clinical focus.

- "She said to me at the end which was quite key of last appointment was, because I was just like "oh now what do I do?" Feeling a little bit lost with this whole thing and, oh that's what I said to her "how can I make, essentially make this, make it get out of my body, release" that's the word I used "how can I release this?" And she said "well in my years of experience and seeing this before, it's not necessarily a releasing it's an acknowledging and then we go from there." So that's what I have been doing. I took that from her and, you know because it's almost like I wanted an outcome to solve it. And she was kind of saying well before the first step is to acknowledge and then, yeah so I think that's how I have managed it really, differently. It's very different to just acknowledge something than to just solve it, it's a very different thing." (Valerie)

A new overarching concept was constructed which speaks to the experience of mutuality in the care experience

On song: the experience of being with a clinician who is fully present and mindful in the clinical encounter.

- "Well you know she's on song, she's seeing me as a patient. She is with me to do that job. So when people are on song it's sort of a unison thing I suppose." (Kathy)
- "Well I think when she is with you she is very much with you. She's not somewhere else. I mean you can just feel she's focused on you as an individual and she's observing all the subtle things that you do without you realising it I think. All the habitual things, the way you sit or whatever. She's observing all of that and taking all of that in and you can only really do that when you are 100% with the patient not thinking of something else or worrying about having to see the next patient or finishing up with the patient before. She does that, she sees people back to back and she cuts off with that person and when you are there she is focused what your problem is or what your issue is." (Jane)
- "There's no judgement, there's presence, full presence... You just know. You can feel it. You know you can feel the difference, you know. Just like that interview with that specialist up at Greenlane there's all sorts of things. It's her body language, it's her eye contact, it's the energy in the room, it's the questions that she asks me." (Valerie)

Patients as partners in their own care: The care experience is a collaborative one. Their expertise in their own bodies and conditions is respected. They are not pushed and rushed towards a specific outcome. As a consequence, they feel in charge and take responsibility.

- "Oh yeah, it's just when your heart is closed I think you are automatically closed to everything around you. But when your heart is open, and I think that happens naturally to a response to someone who has an open heart themselves or who is able to treat you as another human being on the same par as them or just on the same journey as them, then you respond better to whatever it is that you have to. You know there's not the doctors and the nurses up there and I am over here. It's like a group thing you know you deal with it as a group there is that safety in numbers, you feel like you are part of a community and you don't feel isolated then that to me is, automatically your heart opens." (Jane)
- "So it's a very unhappy knee and so it has to be, I have to respect it. And all that she's taught me is how to get square up, how to stand, how to sit, how to, and I have told her that feels absolutely wonderful you can feel yourself grounded. And so what I am saying is I suppose there is a partnership here. There is a partnership. And yeah." (Kathy)

Following this analysis, I felt it was necessary to reflect on the data as a whole.

- How? By writing 3 conceptual memos to push my thinking in depth of concepts that continuously emerged from the data.
 1. On the experience of persons with the clinicians bring the whole of themselves into the encounter. This memo was concerned with professional identities, boundaries and the degree to which those were rigidly held by the clinician and how this was experienced by the person being treated.
 2. On the centrality of the 'story' in the WPTA therapeutic experience from the perspective of the person being treated. Throughout the analysis I used the 'story' aspect of the WPTA as a sensitising concept given the central role the story plays in the writing of Doctor Broom as well as in his questioning of my analysis given his role as a thoughtful clinician.
 3. On first encounters and negotiating the therapeutic relationships. In undertaking this analysis I critically interrogated these descriptions with three key questions in mind:
 1. What happens in that first encounter that shapes the clinical relationship?
 2. What is the role of 'readiness' in these first encounters?
 3. What is the person's view of the centrality of the story in their own illness experience and how does this awareness shape how they come to see their condition?

The process of writing these three overarching memos has resulted in a re-conceptualisation of the data around four overarching thematic sentences.

Seeing patients as persons and explicitly acknowledging their unique illness history as a biographical disruption, is a form of a 'first step' required for patients to be willing to enter and engage in the WPTA experience.

• People with chronic illness often endure a long and turbulent history of experiences with the medical system as well as years of physical discomfort and even suffering. Their illness descriptions evoke notion of chronic-illness as a biographical disruption. An explicit acknowledgment of their personal history as well as illness story and of the therapeutic experiences which may have exacerbated this suffering is in itself experienced as healing and a foreground on which stronger therapeutic relationships can be established.

Patients will engage in the therapeutic experience when clinicians bring the whole of themselves into the therapeutic encounter.

• For the person to experience their care as the care of their whole self, the clinician must also be flexible enough in their professional boundaries to bring key elements of their whole own self into the clinical encounter. Interviewees appear very sophisticated (irrespective of their level of formal education, age or ethnicity) in sensing if the clinician they are seeing is prepared to bring more of themselves into the encounter than the professionally prescribed identity. This in turn appears to influence the ways by which they were prepared to share their whole own self with the clinician, listen, and engage in the care relationship.

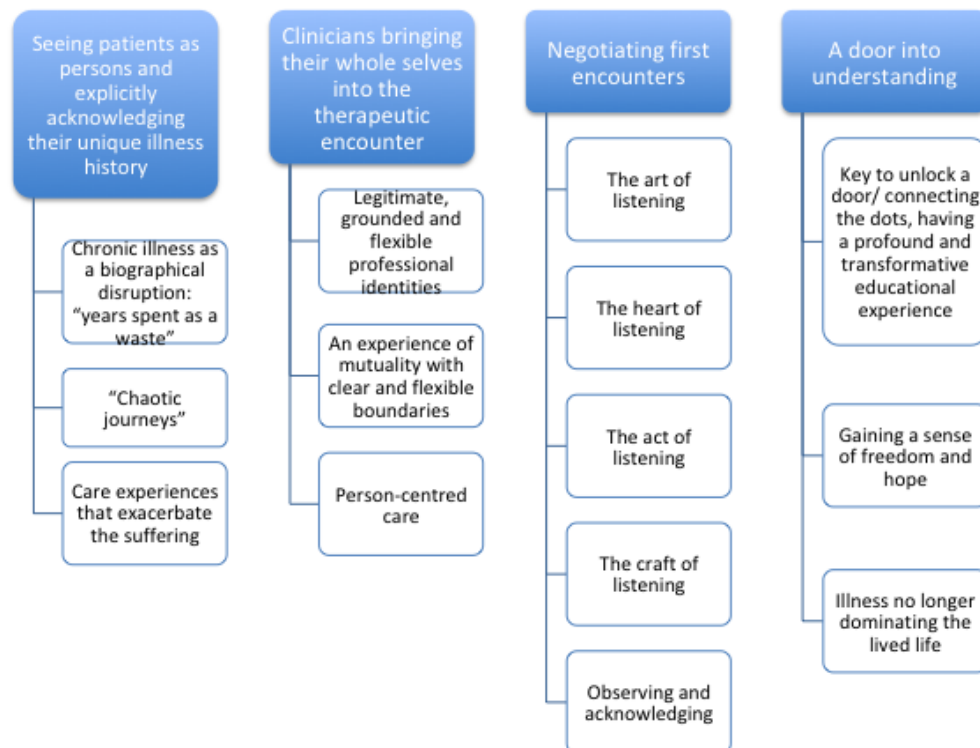
Because the WPTA is experienced in a dualistic mainstream setting, often experienced as a 'shock' by patients, negotiating the first encounters in this context may underscore the success of the treatment.

• I came to understand that stories could be very powerful for the person if first, there is a negotiated understanding between the clinician and the patient about the mind and body links, and this negotiation's success is dependent on the quality of therapeutic relationship. In therapeutic relationship, I refer specifically to the clinician's ability to bring themselves into the encounter and their willingness to listen to the story the person wants to tell.

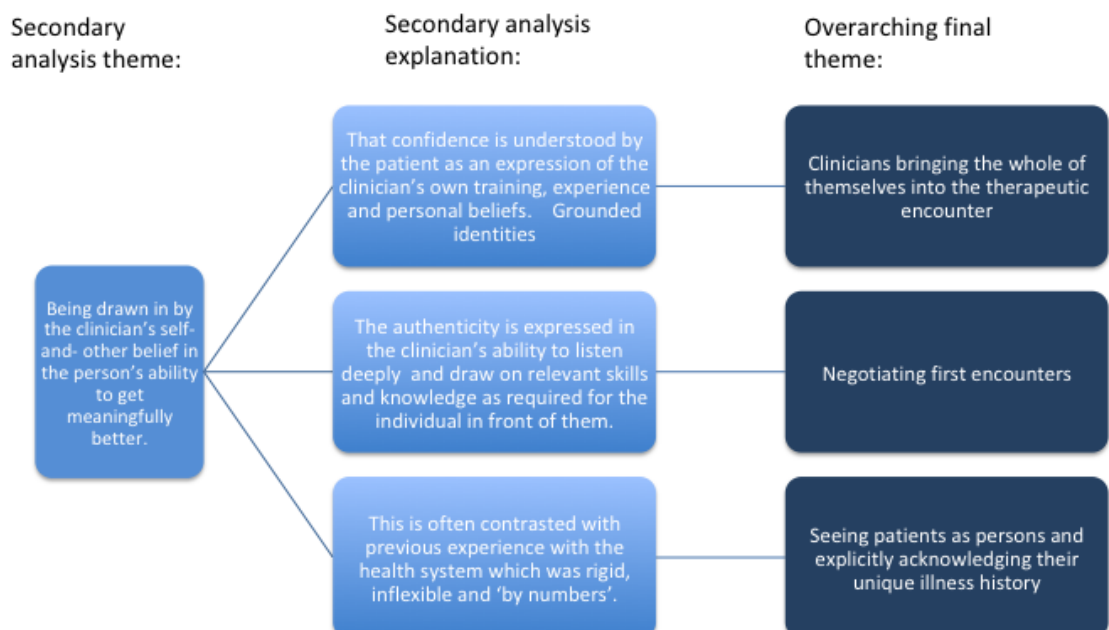
Patients/persons describe the WPTA as providing them with an educational experience conceptualised as a 'door into understanding'; the awareness and subsequent freedom they gain from understanding the mind-body connectivity.

• Throughout the interviews, the most powerful and common thread of the WPTA was how it is experienced as a way to gain a different way for patients to understand their illness in the context of their life. This concept started as a code, then became a theme, and after the memoing analytic process became an overarching concept reflective of its centrality to the experience. Participants described this process with metaphors such as 'unlocking a door' and 'connecting the dots' which speaks to the educational experience of understanding the connectivity.

Which in turn led to re-organising of the (now) sub-themes around the core four overarching themes.



Following this process, I re-examined the secondary analysis findings to see if the overarching themes adequately encapsulate those findings by attempting to map them to one another. (part 1)



Following this process, I re-examined the secondary analysis findings to see if the overarching themes adequately encapsulate those findings by attempting to map them to one another. (part 2)

