Living Well With Complex Regional Pain Syndrome: A Qualitative Exploration of Lived Experiences

A research component submitted to Auckland University of Technology in partial fulfilment of the requirements for the degree of Master of Health Science

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Abstract

Introduction: Complex regional pain syndrome (CRPS) is frequently considered a limiting and distressing condition, and previous qualitative research has highlighted the difficulties of living with CRPS and the shortcomings of healthcare and society. However, there is considerable variability among individuals with CRPS, with some people maintaining meaningful lives despite their condition. Thus far, no study has attempted to understand how people learn to live well despite experiencing long-term CRPS. This information could help inform best practice guidelines and the development of future resources.

Aim: To understand how individuals with long-term CRPS live well despite their condition.

Methods: Participants were New Zealand-based, diagnosed with CRPS (type I or II) more than 12 months ago, and self-identified as 'living well' with CRPS. Data from in-depth interviews were analysed using a reflexive thematic analysis.

Results: Participants (n=10, 70% female) described living well with CRPS as the product of a journey and acknowledged previous times of not living well: "Living *against* CRPS." Living against CRPS was characterised by symptom dominance, forcing the participants to withdraw from fundamental features of their identity and disrupting their sense of self. In contrast, participants described "Living well *with* CRPS" as the restoration of their sense of self by rebuilding purpose and meaning in their lives with the focus on living alongside, in partnership with, their painful limb. Participants described three themes that supported their journey to living well *with* CRPS: 1) *Making sense of my new life with CRPS*: Participants used information obtained through diagnosis, research and social connections to develop a personalised and evolving conceptual model to understand CRPS. 2) *Taking control in a seemingly uncontrollable world*: Participants utilised professional support, evaluated and adopted selected tools for self-management, and recalibrated to a new pace of life in order to take control of their lives. 3) *Rebuilding a purposeful life with a new identity*: Participants described accepting a new life with CRPS and shifting attention to focus on meaningful and purposeful activities, which contributed to a new post-CRPS identity.

Conclusion: 'Living well *with* CRPS' was described as restoring one's sense of self through sensemaking, adjusting, and accommodating to maintain engagement in meaningful activities and life roles.

Table of Contents

List of Figures

List of Tables

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 acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), 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."

Tim McVicar

Publications and Presentations From Thesis

McVicar, T., Bean, D., Lennox-Thompson, B. (2024, March 24). *“It doesn’t define me”: A reflexive thematic analysis of people living well with Complex regional pain syndrome* [Oral presentation]. New Zealand Pain Society Annual Scientific Meeting, Dunedin, New Zealand. https://nzmj.org.nz/journal/vol-137-no-1594/proceedings-of-the-pain-society-asm-2024

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Ethics Approval

Ethics approval was gained on 14 June 2022 by the Auckland University of Technology Ethics Committee (AUTEC). Ethics application number 22/119

Transcription Conventions

The following transcription conventions were used throughout this thesis where direct participant quotes were provided:

“ ”	Denotes a direct quote from the participant
‘ ’	Denotes a quotation within a participant’s direct quote. Where quotations within a quote feature in a block quotation form, the use of “ ” was prioritised
...	Denotes a pause in the participants speech
....	Denotes a word(s) were removed from the original quote
[ ]	Denotes a word added by the researcher for clarification. In addition, if the participant used an identifier in a direct quote, the word was replaced with an anonymised description in square bracket e.g. [healthcare professional]
[sic]	Denotes a quotation error within a direct quote

Abbreviations

A&E	Accident and Emergency Department
ACC	Accident Compensation Corporation
ACT	Acceptance and Commitment Therapy
AUTEC	AUT Ethics Committee
BPI	Brief Pain Inventory
BPS	Biopsychosocial
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
COMPACT	Core Outcome Measurement set for complex regional PAin syndrome Clinical sTudies
CPAQ	Chronic Pain Acceptance Questionnaire
CRPS	Complex Regional Pain Syndrome
CSS	CRPS Severity Score
ePPOC	electronic Persistent Pain Outcomes Collaboration
fMRI	Functional Magnetic Resonance Imaging
GAPPA	Global Alliance of Partners for Pain Advocacy
HCP	Healthcare professional
HIV	Human Immunodeficiency Virus
IASP	International Association of the Study of Pain
ICD	International Classification of Diseases
IL	Interleukin
IPA	Interpretive Phenomenological Analysis
M/F	Male/Female
NHS	National Health Service
NRS	Numerical Rating System
NZE	New Zealand European
NZPS	New Zealand Pain Society
PMP	Pain Management Programme
PROM	Patient Reported Outcome Measure
RNOH	Royal National Orthopaedic Hospital
RSD	Reflex Sympathetic Dystrophy
SNS	Sympathetic Nervous System
TA	Thematic Analysis
TNF	Tumour Necrosis Factor
UK	United Kingdom

WHO	World Health Organisation
Y	Years
y/m	Years/months

Chapter One: Introduction

Complex Regional Pain Syndrome

Complex regional pain syndrome (CRPS) is a rare but debilitating pain condition that can occur after fracture, surgery, stroke or trauma (Bruehl, 2015). Symptoms are commonly isolated to a limb and characterised by continuing pain, disproportionate to any inciting event, with a combination of painful skin sensitivity, changes in temperature and limb colour, increased swelling and sweating of the limb, skin and nail growth changes, and difficulty with movement and perceptual connection to the limb (Goebel et al., 2021). CRPS has a global incidence between 5.6 and 26.2 per 100,000 individuals per year, classifying the condition as a rare disorder (de Mos et al., 2007; Sandroni et al., 2003). However, due to the diagnostic and therapeutic challenges, CRPS is considered a significant health problem for both clinicians and those living with the condition (Ferraro et al., 2024).

In most cases, CRPS symptoms will become chronic, requiring long-term management. Prospective cohort studies indicate that most people have persistent symptoms at 12 months (Bean et al., 2016; Johnson et al., 2022), and while they may improve, their symptoms do not resolve eight years after onset (Cave et al., 2023). The diverse disease mechanisms mean the intensity and degree of persistent symptoms are not equally prominent in all individuals, and the presentation can fluctuate within the same individual over time (Bean et al., 2014; Johnson et al., 2022). Therefore, the extent of disability and one’s ability to cope can vary considerably, ranging from severe distress, including amputation desires, self-harm and suicide (Lee et al., 2014; Lewis et al., 2007; Rodham et al., 2007), to cases where individuals can maintain productive and meaningful lives despite their condition (Bean et al., 2016; Bean et al., 2014; Johnson et al., 2022; Rodham et al., 2013). More recent studies have identified that nearly two-thirds of people working before the onset of CRPS returned to work, with only one-third requiring adaptations (Johnson et al., 2022). Yet, almost nothing is known about this population that appears to ‘cope’ with long-term symptoms as they are largely absent from research.

The vast majority of the available research on CRPS has focused on risk factors, diagnosis and medical management. Whilst this is certainly an important target for future efforts, the current best practice guidelines suggest that the management of CRPS should focus on developing psychological and physical coping strategies, improving function, and reducing the burden of pain to restore a meaningful life (Goebel & Turner-Stokes, 2018; Harden et al., 2022). However, there is limited evidence for such approaches in CRPS and a further lack of foundational knowledge to support people to live well despite their condition (Ferraro et al., 2023; O'Connell et al., 2013). A select few studies have suggested that lower levels of pain, sensory disturbances, disability, body perception disturbances, anxiety and pain-related fear are associated with better outcomes in CRPS (Bean et al., 2015; de Jong et al., 2011; Lewis & Schweinhardt, 2012; Lohnberg & Altmaier, 2013). However, ‘better outcomes’ are not necessarily synonymous with people living well with CRPS (Griffiths et al., 2023b). More importantly, we cannot assume that living well is simply a matter of experiencing fewer symptoms with less distress.

Lived Experience

To date, limited research has explored the lived experience of CRPS. Like much of 20th century chronic pain research, CRPS has been medicalised and emphasised through the hegemony of biomedical frameworks, testing quantitative objective measures that focus on diagnosis, mechanisms, and pharmacological treatment efficacy. Whilst this information is certainly valuable, the experience expressed by those living with CRPS remains poorly understood. In 2015, Colleen Johnston and colleagues completed the first literature review of the available qualitative research on living with CRPS. The authors found only two studies documenting the lived experience of CRPS, concluding, “Until research into the lived experience of CRPS is conducted, we will have only anecdotal evidence on which to base future treatment guidelines” (Johnston et al., 2015, p. 36). The lack of lived experience research on CRPS poses a problem whereby the voices of those living with the condition have no impact on the treatment or approaches provided to them by healthcare professionals. Stephen Butler, a CRPS researcher, made the following comments regarding the literature review by Johnston et al. (2015):

> More information on the “lived experience” of those with CRPS could relieve patient anxiety and make the healthcare system somewhat more sympathetic if it could be available universally… It is also possible that the symptom focus for present treatment is not what patients’ consider the most important and a [qualitative research] study might find another focus for treatment that could be more meaningful for the patient. (Butler, 2015, p. 62)

Learning what works from those living well with the condition may offer additional avenues not seen through clinical trials. Clinical trials often do not represent the ‘real world,’ lack transferability, and, importantly, have limited follow-up post-intervention. Since 2019, the International Association for the Study of Pain (IASP) has recognised the importance of integrating the lived experience of pain into all aspects of research, management and education. The Global Alliance of Partners for Pain Advocacy (GAPPA) was developed to help those living with pain “not just live but live well” (Global Alliance of Partner for Pain Advocacy, 2021, para. 2). GAPPA supports the integration of people with lived experience in designing clinical pain research

(Haroutounian et al., 2024) and healthcare policy (Belton et al., 2023). More importantly, those with experience of living well can offer an untapped resource as they evade our clinical research, and their strategies often remain unknown to those involved in their support and care.

Living Well

Some people live well despite health conditions such as CRPS, and it is possible that much can be learned from these individuals. However, very little research seeks the opinion of those living well with their condition. It would make sense that these individuals were featured less in the research as they are unlikely to be sitting in waiting rooms or attending pain management programmes and thus are less likely to be a burden on clinicians and researchers. Consequently, cohorts in research are typically more distressed, healthcare-seeking and subsequently are less likely to be living well. The outcome is a breadth of literature that is negatively framed, often focussing on the shortcomings of healthcare and society as a whole. Such studies contribute little to the current understanding of how people can live well and maintain meaningful lives despite CRPS.

The topic of living well rarely features in pain management or healthcare settings. Conventional healthcare primarily focusses on relieving disease and pathology to ease an individual’s suffering. Within pain management services, pathology and deficit-based models are common, aiming to identify unhelpful beliefs, maladaptive behaviours, dysfunctional movement patterns, and poor coping (Breivik et al., 2008). The electronic Persistent Pain Outcomes Collaboration (ePPOC), the standard set of outcome measures used to provide benchmarking across New Zealand measures depression, anxiety, catastrophising, pain intensity and co-morbidities (Tardif et al., 2016). The ePPOC requires pain services to measure the deficits associated with pain and therefore focuses clinician attention on attending to deficits rather than recognising strengths. As a form of treatment, individuals are often taught coping strategies to reduce distress and deficits, with the hope of improving pain-related coping and, therefore, their quality of life. However, the absence of disease *does not necessarily* indicate whether someone is thriving (Nutbeam & Muscat, 2021). This message is emphasised in the constitution of the World Health Organisation (WHO):

> Health is a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity. (World Health Organisation, 1946, p. 1315)

Therefore, one could argue that our biomedically structured healthcare system, which focusses on the factors contributing to disease to ameliorate illness, is not designed to support people to live well and thrive in society.

Several models have looked to challenge this biomedically driven, disease-centred view of healthcare. When developing the Biopsychosocial model (BPS), George L. Engel argued that traditional biomedical models leave no room for the psychological, social and behavioural dimensions of illness (Engel, 1977). The BPS model has been widely adopted in the field of chronic pain (Gatchel et al., 2007). Yet, some authors suggest that the model narrowly focusses on biological and cognitive behavioural aspects, negating social influences such as cultural, interpersonal, and institutional factors (Mescouto et al., 2022). Aaron Antonovsky also challenged the pathogenic model of biomedicine in his 1979 book, 'Health, Stress and Coping' (Antonovsky, 1979). Antonovsky developed the term *salutogenesis,* saluto (health) and -genesis (origins), referring to the orientation of health promotion focussing on positive factors and adaptation (Antonovsky, 1979). Salutogenic approaches are now central to the WHO's stance on health promotion, focussing on strength-based approaches that build on coping with life stressors and promoting well-being (Nutbeam & Muscat, 2021). According to Antonovsky, the origins of health (salutogenesis) can be found in the individual's sense of coherence (Antonovsky, 1996). He described a strong sense of coherence across three components:

> Wish to, be motivated to, cope (meaningfulness); believe that the challenge is understood (comprehensibility); believe that resources to cope are available (manageability). (Antonovsky, 1996, p. 15)

Healthcare models promoting resilience and well-being in the face of stressors, such as chronic pain, may enhance self-coherence by orienting life toward being meaningful, comprehensible, and manageable. Therefore, the promotion of strength-based approaches such as resilience may be an important implication for understanding the factors and processes required to achieve a state of living well. Yet, as discussed earlier, these factors are not a priority for healthcare systems and, therefore, feature sparingly across all pain research. Thus, more research is needed to understand the process of living well and how this can be used to promote health and well-being in people living with both chronic pain and CRPS.

Research Gap

Despite the value qualitative research brings, the lived experience literature remains greatly underrepresented in the study of CRPS. Understanding experiences of healthcare, sensemaking approaches to diagnosis, and treatment preferences can only advance our understanding of the experience of living with the condition. Additionally, learning from individuals who live well despite their CRPS could help guide healthcare professionals to support those starting their journey and those finding it difficult to live meaningful lives. To my knowledge, no study has explored those who are living well with CRPS. In the following section, I will describe my professional journey explaining the background of this thesis topic.

My Professional Journey with CRPS

> *The state of empathy, or being empathic, is to perceive the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person, but without ever losing the 'as if' condition.* (Rogers, 1959, pp. 210-211)

Now would be an appropriate time to disclose that I do not have CRPS, nor do I live with chronic pain. I believe it is important to acknowledge that I am an ‘outsider’ (Huxley & Hayfield, 2015). I recognise how this may have implications as a clinician and researcher in CRPS due to the perceived lack of lived experience. I have been humbled by patients saying, “What would you know? You don’t have to live with this.” This is true and undeniable. I am, therefore, ever grateful for the openness and generosity of many of my patients who took the time to share their stories. Without them, I feel I would have much less insight and empathy towards those living with chronic pain and CRPS. I open this section with a quote from Carl Rodgers, the pioneer of person-centred therapy (Rogers, 2000), who describes one of my guiding professional values: empathy. I will elaborate on this in more detail in the positionality section (see page 42), but first, I would like to take the next couple of paragraphs to share my journey as a clinician leading up to this point. I believe it is essential for you to understand my perspective when reading this thesis. I will summarise each section with a reflection, which is an assumption underpinning my positionality as a researcher.

My journey began in 2013 when I started working at a private musculoskeletal physiotherapy clinic catering to what could be described as the ‘worried well.’ Patients would often arrive with self-limiting conditions, request passive interventions, pay their money, and then get on with their lives. I would constantly question whether I was perpetuating their reliance on healthcare and falsely selling a product for many conditions that would resolve without any treatment. Yes, patients were happy, and my employer was happy, but I struggled to see how I was making an impact on the broader landscape of healthcare. I was deeply unhappy at work and often considered leaving the profession.

In 2015, I moved to London, United Kingdom (UK), where I secured a role as a specialist physiotherapist in a tertiary pain service at the Royal National Orthopaedic Hospital (RNOH). The RNOH was a prestigious National Health Service (NHS) trust, accepting referrals from all NHS services across the UK. This service catered to more complex cases of patients who had ‘failed’ secondary care. Overnight, my patient caseload transformed from the ‘worried well’ to complex, co-morbid, and highly distressed. Like many physiotherapists, I found most of my undergraduate training had zero applicability in chronic pain. I recall revisiting my notes from the single undergraduate lecture on chronic pain, reflecting on how unprepared I was. I felt out of my depth, ineffective and frustrated. My patients probably felt the same, seeing my ‘hands-on’ interventions and isolated exercises as a band-aid to a broken bone. I would hear the same narratives from patients: “No one believes me,” “No one is listening to me,” and “Nothing has worked.”

I recall a distressed conversation with my supervisor; in her wisdom, she said, “These patients are not just people in pain… They are mothers, partners, students and football managers who have lost their most valued aspects of life… Maybe we must listen to them and help them feel understood.” Over the next three years, I changed my practice to focus on active listening and demonstrating empathy to understand my patients' perspectives better. I learned these people were not ‘malingers,’ ‘non-compliant,’ or ‘passive.’ They were marginalised individuals who have been stigmatised, discriminated against, and failed by the very healthcare system that was designed to support them. Their pain had become all-encompassing, dominating their life, stripping them of the aspects of their wider identity. Despite their years, sometimes decades, of medical support, they were no closer to their foundational values. They were stuck.

> *Assumption #1: People living with chronic pain are not understood and are poorly supported by our current biomedical frameworks in healthcare.*

On average, people took five years before they were referred to our service. By this time, the medical system had ‘beaten up and spat them out’. They had a long history of treatment-resistant symptoms, often with poor experiences of healthcare. Naturally, many wanted to get out of the healthcare system and manage their lives independently. I could have been mistaken in thinking that biomedical interventions never worked; however, I had to check my bias often and remember that as a tertiary service, we only saw cases that had not improved with primary and secondary care. By this point, many had accepted their condition would not be resolved. Years of unsuccessful medical interventions have demonstrated this. Their goals were often to regain the parts of their lives they valued before pain, such as being a good mother, returning to the football club, and finishing their university degree.

> *Assumption #2: People living with chronic pain often aren’t seeking pain elimination but rather the rebuilding of their lives alongside their pain.*

In 2016, I had the pleasure of leading the RNOH CRPS pain management programme. Interestingly, we received similar feedback from the CRPS cohorts: "For the first time, I felt understood," and "I didn't feel alone." CRPS is a rare condition that neither healthcare professionals nor society understand. People having the opportunity to meet others with the same rare condition and describing similar struggles offered a powerful sense of validation. They often shared self-management tips, which weren't commonly discussed in the textbooks. Often, the patient-to-patient connection was more trusting than the opinions of the healthcare professionals. I learned that lived experience makes you an expert in your condition, and we should see this as a strength to the therapeutic partnership, accessing this resource where possible. I believe GAPPA summarise this insightfully: "When it comes to pain, there is no 'us and them' - there is only 'us' - and we're all in this together" (Global Alliance of Partners for Pain Advocacy, 2019, para. 7).

> *Assumption #3: People living with CRPS are experts in their self-management. We should use their experiences as a resource in collaborative healthcare.*

What captivated me about CRPS was how profound, distressing and disabling the symptoms of CRPS were for some. Yet, others were able to increase their function and coping to the point of maintaining employment. My colleagues and I hypothesised the features consistent with 'copers': resilience, strong social support, and willingness to self-manage. One would assume those with less intense symptoms were more likely to cope; however, counterintuitively, some individuals were seen to be living meaningful lives with highly intense symptoms. Conversely, those with perceived less disease severity could be very disabled by their symptoms. I started to question how we determine severity, disability and coping. I began to understand that pain was a complex experience, difficult to make sense of through basic psychometric tests. We often discussed the notion of 'living well' and what this meant to patients. Interestingly, living well appeared to be different for different people. For some, this meant maintaining good health behaviours; for others, it meant spending more time with their family. It was seldom about living without pain. Less disability was not simply a matter of less intense symptoms. For these people, CRPS became something to be managed alongside their family roles, social lives and employment.

Assumption #4: Living well with CRPS is subjective and independent of disease severity.

I suggest you consider these assumptions as a feature of reflexivity I have taken in the co-construction of knowledge in this thesis. I elaborate further on my views of pain and CRPS, and reflect on these assumptions within the positionality statement. These experiences have also shaped my clinical interests and professional values in healthcare. My values align closely with person-centred and collaborative healthcare, which focusses on strengths and uses the person as an expert in self-management. Importantly, I feel very strongly about the stigmatisation of people with chronic pain in our healthcare system. In the literature review, I will demonstrate how I believe CRPS is stigmatised and discriminated by healthcare professionals and society as a whole. I am passionate about driving change to support this group of marginalised individuals by representing them in a thesis on living well with CRPS.

Overview of This Thesis

This thesis is structured in five parts.

Chapter One, Introduction, has outlined the context and purpose of the topic living well with CRPS. This chapter comprised the rationale for learning from those living well with CRPS, including my personal journey underpinning the idea.

Chapter Two, Literature Review, presents the current evidence of CRPS and its management. I explain the broader view of CRPS, its epidemiology, pathophysiology, and management before presenting a stand-alone systematic literature search and review of the available qualitative lived experience research on CRPS. I finish the section by introducing some contemporary models in the living well literature to provide context and rationale for the aims of the present study.

Chapter Three, Methodology and Methods, introduces the method of Reflexive Thematic Analysis and how this aligns with interpretivist paradigms in qualitative inquiry. It further elaborates on reflexivity in a positionality statement and will describe the ethics, recruitment, data collection, and data analysis phases of the study. I finish this section by detailing steps taken towards study quality.

Chapter Four, Results, describes the overarching theme detailing the journey between living well and not living well. I then present three major analytic themes that describe the process toward living well. It includes quotes and examples to support the findings, illustrated in diagrammatic form.

Chapter Five, Discussion, integrates the study’s findings in the context of current literature. Using existing research, I demonstrate areas that are consistent with previous literature and illustrate the novel findings of this study. Here, conclusions will be drawn about the impact on future healthcare, identifying strengths, limitations, and areas for future research.

Chapter Two: Literature Review

The following chapter provides an overview of the literature related to living well with CRPS. The first section synthesises current evidence and contemporary problems with CRPS in society. This includes the clinical presentation, epidemiology, proposed mechanisms, diagnosis and management. This section aims to provide the context of what is known and what remains unknown to inform future research on CRPS management. The second section describes the literature review, providing a qualitative synthesis of the limited body of literature on living with CRPS. I will highlight gaps in the current literature, using living well with chronic pain literature to emphasise the need for a study on living well with CRPS.

CRPS Literature Synthesis: Setting the Scene

CRPS is a debilitating pain condition with a variable course over time (Goebel et al., 2021). The condition is characterised by continuing, both spontaneous and evoked, regional pain that is not isolated to a dermatome or nerve territory (Goebel et al., 2021). Symptoms most commonly develop in a limb with a distal predominance but, in rare cases, can affect the trunk and face (Ott & Maihöfner, 2018). In addition to pain, CRPS has a combination of sensory disturbances such as allodynia and hyperalgesia; vasomotor changes including altered skin temperature and colour; sudomotor changes including limb sweating and oedema; motor changes including stiffness, weakness, dystonia and tremor; and trophic changes including alterations to skin, nail and hair growth (Goebel et al., 2021). The condition is accompanied with significant emotional distress, impacting activities of daily living and participation in social roles (Goebel et al., 2021; Nicholas et al., 2019).

CRPS can be classified into two subtypes based on the presence or absence of peripheral nerve damage. Type I, formerly known as Reflex Sympathetic Dystrophy (RSD), is the subtype that commonly develops following a noxious event, resulting in disproportionate pain to the injury (Goebel et al., 2021; Stanton-Hicks et al., 1995). Type II, formerly known as Causalgia, presents similarly to type I but is associated with a discrete peripheral nerve injury (Goebel et al., 2021; Stanton-Hicks et al., 1995). Both subtypes have similar management and, therefore, are not often separated within CRPS research (Harden et al., 2022).

History of CRPS

Although CRPS is largely unknown to the public, the condition has a well-documented history referenced in medical literature for over 150 years. Most medical historians agree the first formal articulation of CRPS dates back to 1864 when American Physician Silas Weir Mitchell detailed chronic burning pain and skin disorders following gunshot wounds in the American Civil War (Birklein & Dimova, 2017; Iolascon et al., 2015; Stanton-Hicks, 2019). In his 1864 publication titled 'Gunshot Wounds and Other Injuries of Nerves' Mitchell described:

> The rattling of a newspaper, breath of air, another's step across the ward, the vibration caused by a military band, or the shock of feet in walking, give rise to increase pain. (Mitchell et al., 1864, reprinted in Mitchell et al., 2007, p. 38)

Mitchell later described this painful debilitating condition as 'Causalgia,' stemming from the Greek words for 'heat' (καῦσις [kausos]) and 'pain' (ἄλγος [álgos]) (Iolascon et al., 2015). CRPS-like presentations were also documented in 1900, when Paul Sudeck, a surgeon from Hamburg, documented the acute inflammatory bony atrophy observed on X-rays of patients with limb pain (Stanton-Hicks, 2019). 'Sudecks's atrophy' was later reclassified as RSD after James A Evans, a physician in Massachusetts, observed the pain-relieving effects of sympathetic nerve blocks on patients with Sudeck's atrophy (Stanton-Hicks, 2019). Over the 20th century, CRPS-like presentations have been known under multiple taxonomies, all of which were superseded by technological advancements and diagnostic processes. Some less common examples include shoulder-hand syndrome, algodystrophy and transient osteoporosis (Coderre, 2011). The names RSD and Causalgia remained the preferred terminology for CRPS-like presentations until 1995 (Stanton-Hicks et al., 1995). CRPS is now classified as chronic primary pain in the International Classification of Diseases 11th Revision (ICD-11) under the WHO classification system for chronic pain (Nicholas et al., 2019).

Epidemiology

CRPS is considered a rare condition, with an estimated incidence between 5.6 to 26.2 per 100,000 individuals per year internationally (de Mos et al., 2007; Sandroni et al., 2003). However, condition-specific incidence appears much more frequent, with prospective cohort studies indicating CRPS develops in 3.8-14.0% of wrist fractures (Moseley et al., 2014), 4.4% of surgically treated ankle fractures (Rewhorn et al., 2014), and 8.8% of surgically treated distal radial fractures (Roh et al., 2014). Some authors suggest the incidence is likely underreported in population-based studies due to inconsistencies related to diagnosis and classification (Ferraro et al., 2024; Lunden & Jorum, 2021). New Zealand epidemiological data is sparse; however, 2023 accident-related compensation figures suggest that between 99 to 250 claims for CRPS are accepted annually (Accident Compensation Corporation 2023). However, non-injury-related claims are not covered by The Accident Compensation Corporation (ACC), New Zealand's insurance compensation organisation, therefore true numbers are likely much higher. International compensation data predicts the additional cost of healthcare for those living with CRPS is estimated to be between $3888 - $4845 U.S. dollars per year (Elsamadicy et al., 2018). On average, individuals' healthcare costs are 20% higher for people living with CRPS (Duong et al., 2023). This suggests that despite its rare incidence, CRPS is a major problem for both those living with the condition and society as a whole.

Risk Factors

The reason why some people develop CRPS remains largely unknown. The most commonly reported inciting event is trauma, with fractures (42%), sprains (21%) and surgery (12%) accounting for the majority of cases, with 7% indicating no precipitating event (Ott & Maihöfner, 2018). High pain intensity at the time of trauma has been suggested as a risk factor for developing CRPS. One study finding high baseline pain in the first week following a wrist fracture was strongly predictive of developing CRPS within four months (Moseley et al., 2014). High preoperative pain was also predictive for developing CRPS within six months after total knee arthroplasty (Bruehl et al., 2022). Other cited risk factors include prolonged immobilisation, open fractures, and certain antihypertensive medications (de Mos et al., 2009; Jo et al., 2019; Pons et al., 2015). Genetic studies have revealed associations between CRPS and human leukocyte antigen (de Rooij et al., 2009; van de Beek et al., 2000), including a proposed gene (MMP9) which expressed fourfold higher in people with CRPS (Jin et al., 2013). Certain psychological factors have been postulated to predispose individuals to the development of and severity of CRPS. Following wrist fracture, anxiety, depression, and catastrophising have demonstrated a higher risk of developing CRPS (Farzad et al., 2018; Moseley et al., 2014). Early studies proposed CRPS was attributed to factitious (Taskaynatan et al., 2005) and conversion disorders (Driessens et al., 2002). There has also been an elevated prevalence of post-traumatic stress disorder in people living with CRPS (Speck et al., 2017). However, more robust studies have strongly refuted these ideas, drawing no conclusions from the available literature on an association between the development or maintenance of CRPS and psychiatric co-morbidities (Beerthuizen et al., 2009; Harden et al., 2022). A lot remains unknown about the development of CRPS, with much of the epidemiological and laboratory data offering contradictory opinions, which only further adds credence to the complexity of CRPS.

Outcomes

The majority of people who develop CRPS have chronic symptoms, but how this impacts their lives is less clear. Early prospective studies indicated that the majority of people developing CRPS-related symptoms resolved spontaneously (Zyluk, 1998). However, more recent cohort studies are less optimistic, indicating that only 5.4% of patients were symptom-free at 12 months (Bean et al., 2016). The outcome and extent of symptoms are difficult to predict. In an eight-year follow-up study, Cave et al. (2023) found that mean scores of CRPS severity, pain, disability, and psychological factors improved significantly only during the first 12 months, with no clinically meaningful improvements between one and eight years. The authors noted that those who were less anxious, less disabled and experienced less pain at baseline had better outcomes (Cave et al., 2023). These findings supported earlier literature indicating those with lower levels of pain, sensory disturbances, disability, body perception disturbances, anxiety and pain-related fear were associated with better outcomes at 12 months (Bean et al., 2015; de Jong et al., 2011; Lewis & Schweinhardt, 2012; Lohnberg & Altmaier, 2013). One systematic review of physical and occupational outcomes found that 51-89% of people had ongoing pain and motor dysfunction beyond 12 months, yet 50-60% returned to work, with only half utilising some adaptation to do so (Johnson et al., 2022). Therefore, despite the severe impact, there is variability in CRPS presentations and outcomes, which are not clearly understood.

Pathophysiology

Current evidence suggests that the pathophysiology of CRPS mechanisms is multifactorial (Stanton-Hicks, 2019). Although the precise mechanisms remain unclear, contemporary knowledge suggests the initiation and maintenance of CRPS is related to an aberrant inflammatory response, with sympathetic nervous system, immune system, and central nervous system processes proposed (Ferraro et al., 2024).

1. *Inflammatory response* – In acute CRPS, blood markers reveal elevated interleukin (IL)-8 and tumor necrosis factor (TNF)α receptors and in chronic CRPS, cerebrospinal fluid demonstrates elevated IL-1 and IL-6 (Parkitny et al., 2013). These findings suggest that the onset of CRPS is associated with a predominantly proinflammatory state accounting for the classical hallmarks of oedema, redness, and elevated temperature seen in CRPS.
2. *Sympathetic nervous system* – The vasomotor response of sweating, temperature and blood flow changes have long been postulated as a dysfunctional Sympathetic Nervous System (SNS). Excessive SNS outflow was proposed to explain vasoconstriction and blueish appearance of limbs that were improved by sympathetic nerve blockade (Roberts, 1986). Prior to 1995, the preferred terminology for CRPS-like presentations in the absence of a discrete nerve injury (type I) was RSD, emphasising the assumed importance of the SNS in the condition. Later studies suggest that SNS activity is likely related to the expression of

adrenergic receptors on nociceptors following small fibre nerve injury (Birklein & Schmelz, 2008). Additionally, the role of sympathetic nerve blocks has demonstrated limited efficacy for both pain and function (Ferraro et al., 2023).

3. *Immune response* – More recent biomarker studies have demonstrated increased numbers of $CD4^+$ and $CD8^+$ T lymphocytes, which have a proinflammatory action, in people with chronic CRPS (Russo et al., 2019). Additionally, the observation of immune responses of IgG and IgM immunoglobulins in CRPS-induced rodents supports the notion of an immune response in CRPS (Li et al., 2014). However, the initially promising human intravenous immunoglobin therapy pilot studies (Goebel et al., 2014) were not able to be reproduced in larger randomised controlled trials (Goebel et al., 2018).
4. *Central nervous system* – Central nervous system changes have been proposed in the maintenance of CRPS. One study demonstrated decreased pressure pain thresholds and increased temporal summation of pain during quantitative sensory testing of patients with CRPS (De Schoenmacker et al., 2023). These features of amplification in neural signalling are consistent in central sensitisation causing pain sensitivity (Nijs et al., 2021). Early functional MRI (fMRI) studies demonstrated alterations in the primary somatosensory cortex (S1) cortical region of the affected limb in people with CRPS (Di Pietro et al., 2013). A more recent fMRI study contradicted the findings demonstrated no relationship between S1 hand map measures in CRPS and healthy controls (Mancini et al., 2019). Other MRI studies have demonstrated functional changes in the brain's grey matter of people with chronic CRPS (Pleger et al., 2014) but the significance of this remains unclear.
5. *Psychological factors* – CRPS is accompanied by significant emotional distress. Research has demonstrated high rates of anxiety and depression which may interact with multiple pathophysiological systems (Farzad et al., 2018; Moseley, 2007; Speck et al., 2017). Additionally, factors such as catastrophising may be associated with greater levels of pain and depression associated with greater levels of disability (Farzad et al., 2018; Wertli et al., 2023).

The 20th century has seen research targets broadened from simple peripheral nerve models to more complex whole bodily system processes. However, much of the experimental research demonstrates contradictory findings. The lack of definitive biomarkers may, therefore, be explained by the diverse, widespread, and heterogeneous nature of CRPS as a diagnosis. The current understanding is that CRPS can be viewed as an overprotective automatic response to perceived threat. The body tries to protect a painful limb through multiple defence systems, including proinflammatory responses, SNS excitability, autoimmune responses and sensitisation of the nervous system (Birklein & Schmelz, 2008; De Schoenmacker et al., 2023; Parkitny et al., 2013; Russo et al., 2019). The person henceforth develops functional brain changes to promote avoidance of dangerous movements by altering the somatosensory representation of the limb (Moseley, 2007).

Diagnosis

One of the largest challenges in CRPS management is the lack of a 'gold standard' test to diagnose CRPS. CRPS is a clinical diagnosis, meaning there is no blood test, biomarker, imaging or genetic test that can definitively confirm the diagnosis. The Budapest (Harden et al., 2010b) and more recently updated Valencia criteria (Goebel et al., 2021) confirm a diagnosis based on a collection of signs observed by the clinician and symptoms reported by the patient in the absence of any other disease (see Table 1). The current criteria are the product of successive phases of research without a unifying theoretical model, leading to multiple management approaches similarly lacking in coherence. As such, there are inherent ambiguities and discrepancies between the criteria's application, likely related to the incomplete understanding of pathophysiological mechanisms and the multiple interacting systems involved (Ferraro et al., 2024). The difficulties in recognising and diagnosing CRPS have negative impacts on those living with the condition. Two Norwegian studies found that people took between 2.1 to 3.9 years to receive a diagnosis (Lunden & Jorum, 2021; Lunden et al., 2016). Delays in diagnosis can lead to unnecessary and harmful interventions. In their 2016 study, Lunden and colleagues found that 27 out of the 55 participants had undergone surgery in the form of neurolysis, decompression, scar tissue removal and neuroma excision. In some instances, participants were operated on 12 times with 81.5% experiencing worse pain post-surgery (Lunden et al., 2016). As prompt diagnosis and management are considered best practice in all treatment guidelines (Goebel et al., 2018; Harden et al., 2022) it is worth considering why so many people living with CRPS continue to report extensive delays in receiving a diagnosis. A 2008 study found that many healthcare professionals remain uncertain or sceptical of the presentation (McCabe & Blake, 2008). A more recent 2016 survey of 241 international health professionals and academics demonstrated that nearly half of the participants expressed difficulty in recognising the symptoms of CRPS (Grieve et al., 2019). Borchers and Gershwin (2014) attribute some of the ongoing confusion to the continual use of outdated taxonomy in present-day publications[1].

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[1] An example of outdated taxonomy:

- Del Piñal F. (2022). Outcomes of Carpal Tunnel Release in Complex Regional Pain Syndrome/Reflex Sympathetic Dystrophy/Sudeck Disease Patients. *Plastic and reconstructive surgery*, *150*(1), 93–101. https://doi.org/10.1097/PRS.0000000000009243

The difficulties with diagnostic clarity and standardised terminology for chronic pain conditions was the primary goal for the establishment of the IASP in 1973. Developing standardised taxonomy and diagnostic criteria for several chronic pain conditions would in turn improve the effectiveness of clinical trials and develop optimum treatments for patients with chronic pain. The IASP met in Orlando in 1994 where the name ‘complex regional pain syndrome’ was created (Stanton-Hicks et al., 1995). ‘Complex’ refers to the diverse and limited understanding, ‘regional’ suggests symptoms are typically limited to one body region and ‘pain syndrome’ emphasises pain as the primary symptom and syndrome refers to a set or association of symptoms or conditions (Stanton-Hicks et al., 1995; Stanton-Hicks, 2019). The IASP used CRPS to encompass both previously known RSD and Causalgia into type-I and type-II subgroups through a criterion of self-reported symptoms (pain, sensory changes, swelling and blood flow asymmetries) known as the Orlando criteria (Stanton-Hicks et al., 1995). However, Norman Harden and Stephen Bruehl, two CRPS researchers from the USA, demonstrated challenges in the Orlando criteria where people experiencing non-CRPS neuropathic pain (e.g. diabetic neuropathy, post-herpetic neuralgia) met the criteria 40% of the time (Bruehl et al., 1999; Harden et al., 1999). In 2003, Harden proposed the addition of clinical signs in conjunction with self-reported symptoms in an updated criteria in Budapest in 2003 (Harden et al., 2010b). The modified ‘Budapest Criteria’ had a significantly greater specificity where non-CRPS patients were correctly not diagnosed 97% of the time, reducing misdiagnosis (Harden et al., 2010b). In 2019, the IASP CRPS Taskforce met to discuss inconsistencies behind the classification of CRPS under ‘diseases of the autonomic nervous system’ in the WHO ICD-10. Neuropathic pain, by its definition, was diagnosed by a lesion in the nervous system (Jensen et al., 2011), and CRPS-type I was differentiated by the absence of nerve injury or identifiable nerve lesion (Harden et al., 2010b). Additionally, the neuropathic-like symptoms in CRPS commonly spread beyond the expected nerve lesion distribution (Goebel et al., 2021). Therefore, the most recent diagnostic guidelines, the Valencia criteria[2], was developed to stipulate that CRPS was not a form of neuropathic pain and therefore required separate CRPS classification (Goebel et al., 2021). In the updated ICD-11, CRPS was added to a newly developed umbrella category, ‘chronic primary pain,’ to classify painful conditions associated with significant emotional distress or functional disability that cannot be explained by another chronic pain condition (Treede et al., 2019).

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[2] The Valencia criteria changes included:

- CRPS type I and II were proposed to be classified as chronic primary pain in the ICD-11.
- CRPS type II should not be classified as a neuropathic pain condition.
- A third type of CRPS, ‘CRPS with Remission of Some Features’, was developed for those who no longer sufficiently meet the criteria for diagnosis.

Given the history of frequent changes in taxonomy and diagnostic criteria, it may not come as a surprise that CRPS remains a clinical conundrum for healthcare professionals and researchers alike. The unfortunate consequence is that people living with the condition are often diagnosed late, receive inappropriate or harmful treatments, and delay receiving best practice care (Lunden & Jorum, 2021; Lunden et al., 2016).

Table 1

Budapest Clinical Diagnostic Criteria for CRPS

1	Continuing pain, which is disproportionate to any inciting event
2	Must report at least one symptom in *three of the four* following categories: • *Sensory:* reports of hyperesthesia and/or allodynia • *Vasomotor:* reports of temperature asymmetry and/or skin colour changes and/or skin colour asymmetry • *Sudomotor/oedema:* reports of oedema and/or sweating changes and/or sweating asymmetry • *Motor/trophic:* reports of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)
3	Must display at least one sign at time of evaluation in *two or more* of the following categories: • *Sensory:* evidence of hyperalgesia (to pinprick) and/or allodynia (to light touch and/or deep somatic pressure and/or joint movement) • *Vasomotor:* evidence of temperature asymmetry and/or skin colour changes and/or asymmetry • *Sudomotor/oedema:* evidence of oedema and/or sweating changes and/or sweating asymmetry • *Motor/trophic:* evidence of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)
4	There is no other diagnosis that better explains the signs and symptoms

Retrieved from "Validation of proposed diagnostic criteria (the "Budapest Criteria") for Complex Regional Pain Syndrome" by N. R. Harden et al., 2010, *Pain*, *150*(2), 268-274. Copyright (c) 2010 by the International Association for the Study of Pain.

Note. The Budapest Criteria remains the cited eligibility criteria for ACC-funded pain management services within New Zealand (Accident Compensation Corporation 2024). The Valencia Criteria superseded the Budapest Criteria in 2021; however, the signs and symptom checklist remained unchanged.

Management

There is no cure for CRPS, with the majority of the treatments aimed at reducing the impact of symptoms (Goebel & Turner-Stokes, 2018; Harden et al., 2022). In 1997, an IASP Special Taskforce created the Malibu CRPS treatment algorithm, which included functional restoration, pharmacology and psychotherapy (Stanton-Hicks et al., 1998). Since then, several updated guidelines include the addition of interventional and interdisciplinary treatments (Goebel & Turner-Stokes, 2018; Harden et al., 2022; Harden et al., 2013). In 2018, the Royal College of Physicians (UK) developed best practice guidelines using the highest quality of evidence available (Goebel & Turner-Stokes, 2018). They identified pillars of management for CRPS as education, pain relief, physical and vocational rehabilitation and psychological interventions:

1. *Patient information and education* – Education forms the first line of management across most guidelines (Goebel & Turner-Stokes, 2018; Harden et al., 2022). Concepts such as causes, prognosis, self-management strategies, social support, keeping active, and understanding the multidimensional nature of symptoms have been deemed 'very important' for people living with CRPS (Moore et al., 2023).
2. *Medication and procedures* – Oral, intravenous and topical pharmacotherapies; interventional procedures (e.g. nerve blocks); and neuromodulation (e.g. spinal cord stimulators) are primarily used for pain relief and supporting rehabilitation (Goebel & Turner-Stokes, 2018; Harden et al., 2022). However, there are very few studies that demonstrate convincing efficacy for any of these interventions. The majority of the research is underpowered with only short-term follow-up. Two Cochrane reviews state there is a lack of high-quality evidence for the effectiveness of most treatments for pain and disability in CRPS (Ferraro et al., 2023; O'Connell et al., 2013).
3. *Physical and vocational rehabilitation* – Both physiotherapy and occupational therapy is recommended for acute and long-term cases to address functional needs, provide self-management strategies and liaise with community supports (Goebel & Turner-Stokes, 2018). There is single clinical trial evidence to support specific interventions such as graded motor imagery (Moseley, 2004), mirror visual feedback (McCabe et al., 2003), tactile discrimination (Moseley et al., 2008), and sensory retraining for body perception disturbances (Lewis et al., 2007; Lewis et al., 2011). However, both sample size and effects size remain small in all of these trials. A recent Cochrane review concluded that the effects of physiotherapy on pain and disability were uncertain due to the lack of high quality evidence available (Smart et al., 2022). A recent systematic review of non-pharmacological treatment of upper limb CRPS determined that movement, desensitisation and graded functional activity were common treatments but the methodological quality of studies was poor (Griffiths et al., 2023b). Many treatment guidelines recommend a combination of graded activity and functional restoration (Goebel & Turner-Stokes, 2018; Harden et al., 2022).

4. *Psychological interventions* – Psychological interventions are recommended to identify psychological factors that may contribute to the persistence of pain and disability, such as depression and anxiety, fear avoidance, catastrophising, and unhelpful coping strategies (Turner-Stokes & Goebel, 2011). Cognitive behavioural therapy (CBT) has demonstrated small benefits in pain and disability in chronic pain populations (Williams et al., 2020). More recent therapies, such as Acceptance and Commitment therapy (ACT), have demonstrated positive effects on single clinical trials (Williams et al., 2020).

Much like the multifactorial nature of mechanisms and pathophysiology, the treatment for CRPS requires a multifaceted approach provided in an interdisciplinary manner (Harden et al., 2022; Turner-Stokes & Goebel, 2011). The interdisciplinary team can support and optimise function, provide limited pain relief, but treatment outcomes are far from satisfactory.

In this section, it is evident the emphasis researchers have placed on the risk factors, pathophysiology, diagnosis and management of CRPS. Advancements in specific research fields have gone a long way to help understand the condition and its multiple mechanisms accounting for the clinical presentation. However, if mechanisms remain unexplained, directly addressing these factors is difficult, and with a paucity of theoretical models explaining distress and disability in people with CRPS, coherent treatment models to support people with CRPS are undeveloped. The current guidelines suggest people living with CRPS should focus on developing psychological and physical coping strategies, improving function and reducing the burden of pain to restore a meaningful life (Goebel & Turner-Stokes, 2018; Harden et al., 2022). Yet, there is so little evidence on how people living with CRPS can restore meaning in their lives and an even further lack of foundational knowledge to support people to live well despite their condition (Ferraro et al., 2023; O'Connell et al., 2013). Much of the available literature on such approaches focusses on reducing distress and coping with symptoms. However as discussed earlier, reduction in distress and greater coping are *not necessarily* synonymous with living well.

Systematic Literature Review: The Lived Experience of CRPS

Thus far, I have described the overwhelming dominance of biomedically-orientated research on CRPS. While this information is beneficial, understanding the patient perspective or lived experience of CRPS is under developed. The question remains: how do we know what is actually important for people living with CRPS? As discussed in the introduction, Johnston et al. (2015) emphasised the underrepresentation of qualitative literature on CRPS, finding just two studies in their narrative synthesis exploring the lived experience (Rodham et al., 2012; Rodham et al., 2013).

The authors included 10 studies that looked at the lived experience of other chronic pain conditions to build an evidence base for living with CRPS. Similar themes of invisibility, disbelief, coping with a non-compliant body, pain alleviation and self-management were evident across both CRPS and chronic pain studies (Johnston et al., 2015). The authors proposed people living with CRPS experienced a loss of their former healthy, pain-free self whilst working towards acceptance of their new identity. These findings highlight that CRPS is not just a painful disorder but rather a life-changing condition that impacts their independence, relationships and broader aspects of their identity.

Since 2015, significant momentum has been gained in the lived experience research of CRPS. However, there has been no updated qualitative synthesis since the review by Johnston et al. (2015). An updated perspective on living with CRPS could build on the previously inferred themes and assist in balancing the predominance of quantitative research aiming to support those living with CRPS. The following section will outline an updated literature search on lived experience CRPS studies.

Literature Search

Literature searches were conducted between May 2022 and January 2024 using the databases: EBSCO (CINAHL, MEDLINE, SPORTDiscus), PsycINFO, Scopus and Google Scholar. Key search terms included: “Complex Regional Pain Syndrome” OR “CRPS” OR “Reflex Sympathetic Dystrophy” OR “RSD” OR “Causalgia[3]” AND “Lived Experience” OR “Life experience” OR “Patient experience” OR “Phenomenolog*” OR “Qualitative.” For pragmatic reasons, only English articles were selected, and those involving adult participants. Studies were excluded if they did not clearly include a diagnostic criteria (e.g. Budapest criteria) for inclusion; if there were mixed populations (e.g. chronic pain and CRPS) due to the difficulty of analysing specific data; if they looked at experiences post-intervention (e.g. spinal cord stimulator); and if they did not feature lived experience qualitative literature (e.g. some mixed-method studies).

Study Characteristics

Thirteen qualitative or mixed-method studies were found using the defined inclusion criteria. The details of the study design, characteristics, main ideas and quality score are summarised in Table 2. Studies included the experiences of living with CRPS (Antunovich et al., 2021; Beales et

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[3] The condition now termed complex regional pain syndrome (CRPS) has multiple taxonomies spanning more than 150 years. The most common alternate terms used are Reflex Sympathetic Dystrophy (RSD) and Causalgia. See the start of Chapter Two for further information.

al., 2021; Johnston-Devin et al., 2021; Kwon & Kim, 2021; Rodham et al., 2013), receiving information about CRPS (Grieve et al., 2016), diagnosis and healthcare for CRPS (Griffiths et al., 2023a; Raja et al., 2021), attending and transitioning home after a CRPS pain management programme (Johannesson et al., 2023; Rodham et al., 2012), and intimacy in relationships for people with CRPS (Packham et al., 2020). One study was excluded because the data were primarily from online storyboards and blogs, and there were minimal parallels to living well with CRPS (Rodham et al., 2009). The aforementioned 2015 narrative synthesis by Johnston et al. (2015) was also excluded, as this featured two of the included studies (Rodham et al., 2012; Rodham et al., 2013) and 10 non-CRPS studies. There were no studies that examined the concept of living well with CRPS.

Literature Quality

The quality of literature was screened using the Critical Appraisal Skills Programme (CASP) qualitative study checklist (Critical Appraisal Skills Programme, 2018) displayed in Table 3. The CASP qualitative study checklist is a 10-question tool that appraises the strengths and limitations of qualitative research (Long et al., 2020). Of the eleven studies, CASP scores ranged from 5/9 to 9/9, where 9/9 is the highest quality. Two studies did not adequately state their methodology (Raja et al., 2021), with three failing to demonstrate robust data analysis by adhering to methodological rigour (Antunovich et al., 2021). Four studies failed to critically identify their role as researchers (Grieve et al., 2016; Kwon & Kim, 2021), and their relationship to participants (Rodham et al., 2012; Rodham et al., 2013). Two studies did not clearly describe their recruitment strategy (Raja et al., 2021), and three demonstrated unclear data collection practices (Antunovich et al., 2021; Johnston-Devin et al., 2021; Packham et al., 2020).

Table 2

Summary of Findings From Literature Search

Author (Country)	Concept	Methodology and Method	Sample	Summary	Relevance to living well with CRPS			Study quality: CASP score
					Note 1	Note 2	Note 3	
Antunovich et al. (2021) New Zealand	To explore the experiences of people living with CRPS through interviews and drawings	Qualitative design Reflexive thematic analysis of semi-structured interviews	*n* = 48 (71% F) Age: 50.9y Duration: 5.25y	CRPS is a source of severe symptoms and emotional distress which undermines personal and social identities	CRPS disrupted their lives and drew them away from their self-identity	People felt isolated, lonely and judged by society and healthcare professionals	People developed protective psychological responses to lessen the impact	CASP 7/9 – Unclear data analysis and data collection
Beales et al. (2021) Australia	To explore the experiences of people living with CRPS in Australia	Qualitative design Thematic analysis of in-depth interviews	*n* = 15 (80% F) Age: 42.7y Duration: 3.8y	CRPS impacts self-identity and valued activities. People had to adapt to a living with restrictions, whilst making sense of their condition to find a way toward acceptance	People needed to make sense of CRPS. This was achieved through gaining knowledge and understanding, whilst dealing with the unpredictability	Acceptance was an important of the journey with trial and error of various coping strategies	People perceived healthcare as positive if they had experience managing CRPS, used simple language, showed empathy and compassion.	CASP 8/9 - Unclear data analysis
Grieve et al. (2016) United Kingdom	To explore the information needs of people living with CRPS	Qualitative design Thematic analysis of semi-structured phone interviews	*n* = 8 (100% F) Age: 44y Duration: 5.4y	People living with CRPS were given limited information at the time of diagnosis. They needed to seek information themselves	People felt uninformed by healthcare professionals: they wanted access to truthful information about CRPS and its impact on their lives	People felt healthcare professionals were also uninformed: they wanted to find those with expertise	People wanted honest, accurate information about CRPS and its outcomes.	CASP 8/9 – Unclear relationship between researcher and participants
Griffiths et al. (2023a) New Zealand	To explore the experience of diagnosis and treatment for people with upper limb CRPS in New Zealand	Qualitative design Reflexive thematic analysis of semi-structured interviews	*n* = 13 (85% F) Age: 55y Duration: 19m	CRPS alters people sense of self, through the loss of occupations roles and ways of doing.	People desired information and to be actively involved in their healthcare	People wanted to be treated like a person including being listened to, and validated with information presented consistently	People engaged with healthcare to navigate towards valued life roles	CASP 9/9

Author (Country)	Concept	Methodology and Method	Sample	Summary	Relevance to living well with CRPS			Study quality: CASP score
					Note 1	Note 2	Note 3	
Johannesson et al. (2023) Sweden	To explore the experiences of people with CRPS attending a PMP	Qualitative design Applied thematic analysis of semi-structured interviews	*n* = 10 (?% F) Age: 40.9y Duration: 5.3y	Attending a PMP improved daily functioning by reducing pain-related fear and reaching acceptance of their condition	Acceptance of CRPS was associated with a greater quality of life	Gaining knowledge about CRPS was important for reducing pain-related fear	Social connection in the PMP offered a shared understanding and tips for management	CASP 7/9: Unclear data analysis and recruitment strategy
Johnston-Devin et al. (2021) International	To understand the phenomenon of chronic pain by exploring the experiences of people living with CRPS	Qualitative design Hermeneutic phenomenological study of in-depth interviews	*n* = 17 (82% F) Age: 41y Duration: 7.2y	Living with CRPS was described as a constant battle, akin to war, fought by those with limited preparation, resources on shifting terrain	People describe CRPS as an unknown condition, with conflicting and confusing advice. They need to advocate for themselves and seek good healthcare and social support	People have to deal with accepting less from their body, pacing themselves, negative psychological impacts and judgements from others	People report limited control, with fear of spread, with many interventions ineffective or with side effects	CASP 8/9 - Unclear data collection
Kwon and Kim (2021) Korea	To explore the experiences and challenges of people living with CRPS in Korea	Qualitative design Thematic analysis of semi-structured interviews	*n* = 11 (45% F) Age: 43y Duration: 6.2y	People living with CRPS typically endured internal difficulties alone. This included finding their own ways for pain relief, psychological and social support	People had poor understanding of CRPS which contributed to physical and psychological hardship	People desired acknowledgement, understanding and compensation whilst remaining cautious of disclosure	People developed their own strategies for pain relief. This included protection and living carefully	CASP 7/9 - Unclear data analysis and relationship of researcher and participants
Packham et al. (2020) Canada	To explore the impact of painful sensitivity and other associated symptoms on intimacy for people living with CRPS	Qualitative design Codebook thematic analysis of semi-structured cognitive interviews	*n* = 44 (91% F) Age 47.8y Duration: not stated	CRPS impacts relationships and the activities and roles involved in intimacy. People with CRPS have to renegotiate their social identity including reinventing their intimate self	Renegotiating the social identity was necessary due to the loss of control, limited understanding, loss of intimacy and changes to relationship roles	People with CRPS reinvented their intimate self by self-preservation and making adjustments to new levels of function	People also reinvented their intimate self by reframing intimacy broader than sexuality, changing intimate behaviours and emotional connection to sex	CASP 7/9 - Unclear data collection and data analysis

Author (Country)	Concept	Methodology and Method	Sample	Summary	Relevance to living well with CRPS			Study quality: CASP score
					Note 1	Note 2	Note 3	
Raja et al. (2021) United States of America	To explore the unmet needs of healthcare for people with CRPS, support persons and HCPs	Mixed methods Thematic analysis of semi-structured interviews	*n* = 20 (90% F) Age: 80% between 26-64y Duration: 50% over >5y	The unmet needs of people living with CRPS are characterised by disappointing healthcare encounters, and personal and relational loss	People living with CRPS want an early diagnosis and information to help understand CRPS and guide the healthcare journey	People want access to the highest quality care including healthcare professionals who treated the condition and not the symptoms, listened, and understood their situation	People report loss of individuality, identity, independence, intimacy and integrity. They want CRPS networks and advocacy groups to connect with other patients	CASP 5/9: Unclear methodology, study design, recruitment strategy, and data analysis
Rodham et al. (2012) United Kingdom	To explore the experiences of people transitioning home following an inpatient CRPS PMP	Qualitative design Interpretative phenomenological analysis of semi-structured interviews	*n* = 10 (90% F) Age: 42y Duration: 5.1y	Attending the PMP provided people with a sense of control and validation of their condition. Progress was difficult to maintain on discharge due to lack of ongoing support	Maintaining the momentum was difficult due to the lack of local expertise. Many felt they regressed without the speciality support	Limited access to local resources e.g. gym, pool were factors in difficulty maintaining progress	Lack of routine and limited social support were factors in maintaining adherence	CASP 8/9 – Unclear relationship of researcher and participants
Rodham et al. (2013) United Kingdom	To explore the advice provided from patients to patients about coming to terms with chronic CRPS	Qualitative design Thematic analysis of semi-structure interviews	*n* = 21 (76%F) Age: 45y Duration: 3.25y	Playing an active role and taking control of their situation were common in the advice provided from patients to future patients	Acceptance was an important prerequisite to taking control. Acceptance required a diagnosis and recognition there was no cure	Gaining the right support facilitated taking control. The right support included healthcare professionals and social supports being available and understanding	Becoming informed included increasing their understanding through good quality information hoping to become their own expert	CASP 8/9 – Unclear relationship of researcher and participants

Note. CRPS = Complex Regional Pain Syndrome. *n* = Sample size. %F = Percentage of the sample that are female. y/m = Years/Months. CASP = Critical Appraisal Skills Programme. HCPs = Healthcare Professionals. PMP = Pain Management Programme.

Table 3

Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist

Author	Aims	Methodology	Design	Recruitment	Data collection	Researcher relationship	Ethical considerations	Data analysis	Findings	Total
Antunovich et al. (2021)	✓	✓	✓	✓	-	✓	✓	-	✓	7/9
Beales et al. (2021)	✓	✓	✓	✓	✓	✓	✓	-	✓	8/9
Grieve et al. (2016)	✓	✓	✓	✓	✓	-	✓	✓	✓	8/9
Griffiths et al. (2023a)	✓	✓	✓	✓	✓	✓	✓	✓	✓	9/9
Johannesson et al. (2023)	✓	✓	✓	-	✓	✓	✓	✓	✓	8/9
Johnston-Devin et al. (2021)	✓	✓	✓	✓	-	✓	✓	✓	✓	8/9
Kwon and Kim (2021)	✓	-	✓	✓	✓	-	✓	✓	✓	7/9
Packham et al. (2020)	✓	✓	✓	✓	-	✓	✓	-	✓	7/9
Raja et al. (2021)	✓	-	-	-	✓	✓	✓	-	✓	5/9
Rodham et al. (2012)	✓	✓	✓	✓	✓	-	✓	✓	✓	8/9
Rodham et al. (2013)	✓	✓	✓	✓	✓	-	✓	✓	✓	8/9

Note. ✓ = “yes” . - = “no,” or “can’t tell” in the CASP Qualitative Checklist

Results

Living with CRPS was a challenge due to the severe physical symptoms and subsequent emotional impact. People described a widespread negative impact, including the withdrawal of valued activities and changing their identity and self-concept. People felt uninformed and struggled to access appropriate information. To compound this, healthcare was often disappointing unless seen through speciality services. The reference to coping and self-management was sparsely discussed and the focus of only one study (Rodham et al., 2013). These topics have been expanded into broad themes below.

Severe Physical and Emotional Impact Not Understood by Others. CRPS is a condition characterised by severe physical symptoms. All eleven studies emphasised that CRPS is primarily a chronic pain condition with unpredictable symptoms. In a study of 17 people living with CRPS, Johnston-Devin et al. (2021) depicted life as a constant battle, illustrating war-like themes including ‘battles within a war’ and ‘dealing with an unknown enemy.’ The authors highlighted the unrelenting, encompassing nature of CRPS in a final theme named ‘becoming a prisoner of war.’ The all-consuming, day-by-day burden was also echoed by Beales et al. (2021), where one participant spoke about the psychological effects of unpredictable symptoms, “It just doesn’t go away, you know, so sometimes it, the pain… it would just go on and on, you know for like that high intense stuff. And so yeah, I fell down a bit of a rabbit hole psychologically” (P15F) (p. 400). Both studies adopted a self-referral recruitment strategy through social media. Whilst social media is a convenient way to identify people living with a rare condition, other non-CRPS-related studies have demonstrated that social media self-referral typically recruits a more distressed cohort with amplified condition-related difficulties (Benedict et al., 2019). Therefore, such populations may not represent those who are living well with CRPS.

Severe physical symptoms contribute to emotional and psychological distress. Two studies highlighted the negative psychological impact of living with CRPS (Antunovich et al., 2021; Kwon & Kim, 2021). The participants in Kwon and Kim (2021) defined pain as “a form of personal suffering” (p. 3). Many described an internal conflict between disclosure and hiding their suffering: “They look at you like you’re abnormal, so I prefer not to say anything” (Participant 6) (p. 5); consequently, participants often endured suffering alone. The authors summarise the conflicting desire to be understood whilst avoiding misguided preconceptions about CRPS can contribute to complex psychological problems. Antunovich et al. (2021) documented how CRPS could make participants feel at their lowest, often considering ending their lives: “We call it the suicide illness—it pushes people to do it because people make them feel like they are crazy and isolated” (No name) (p. 3012). Both studys’ participants were actively attending tertiary, hospital-level pain management centres. These services are typically reserved for more distressed and complex cases. Therefore, these themes may not be generalisable to populations who are not seeking healthcare, who may be assumed to be coping and self-managing with long-term CRPS.

Changes to Identity and Self-Concept. The physical limitations imposed by CRPS often force the withdrawal of valued activities, profoundly impacting people's identity and self-concept. All eleven studies described the wider impact of CRPS on their identity, with two studies exclusively exploring the changes in the perception of personal and social identities (Antunovich et al., 2021; Johnston-Devin et al., 2021). The most prevalent theme was the loss of their pre-CRPS identity. One participant in Johnston-Devin et al. (2021) described loss as more than just the physical deficits, “Yeah, I lost everything. I've lost work, I've lost everybody I worked with. I've lost most of my friends. I've lost them. I haven't lost all my friends I still speak to them I just don't see them. My fault not theirs” (Karen) (p. 1120). One participant in Antunovich et al. (2021) discussed loss in terms of their sense of self, “The pain and everything has taken me away from who I was and who I am. It has made me feel very vulnerable and very weak. I don’t identify with it” (no name) (p.3013). Across all studies, the limitations imposed by CRPS conflicted with individuals' personal views of themselves. People found it difficult to accept the new person they had become. Raja et al. (2021) noted that people struggled to accept the change from ambitious, productive and free individuals to static and dependent patients who were now a burden on others. Beales et al. (2021) concluded that living with CRPS was about accepting alterations to one’s identity and self-concept whilst learning to navigate their ‘new normal.’ However, how one becomes more accepting to undesired alterations and navigates their ‘new normal’ remains unclear.

Changes to Social Roles and Relationships. The impact of CRPS extends beyond the individual into social and intimate relationships. Three studies explored the general impact on spousal relationships (Beales et al., 2021; Johnston-Devin et al., 2021). Due to their incapacity, people often reported feeling like a burden to their family members (Beales et al., 2021; Johnston-Devin et al., 2021; Raja et al., 2021). Commonly, the lack of visible disability and lack of understanding created tension and stress among family members (Beales et al., 2021). Johnston-Devin et al. (2021) featured the sense of guilt when participant Karen said, “You don't feel like you're pulling your weight” (p. 1120). Raja et al. (2021) explored how the support person often had to withdraw from hobbies and work, which created relationship tension and negatively impacted the support person's identity. The authors termed this “second-hand CRPS” (p. 2395), adding further reference to the widespread impact of CRPS on individuals and their families.

Two studies explored the challenges people face in maintaining intimacy with CRPS (Packham et al., 2020; Raja et al., 2021). Packham et al. (2020) found that painful sensitivity, or allodynia, impacted the frequency of intimate interactions and changed how they perceived their intimate identities. Participant Michelle described guilt and self-stigma: “Others that are normal see you as a disability, and a disability is like having an ugly thing on your body. They don’t want to be with somebody like that” (p. 243). Although the data were limited, as this was a secondary study of an outcome measure, themes of guilt and self-stigma were prevalent across all participants. Raja et al. (2021) identified that the loss of intimate identity extended beyond the individual, noting that spousal relationships transitioned from romantic (intimate) to carer (non-intimate). Despite the authors not including any supporting participant quotations with questionable methodological rigour, the theme of relationships moving from transformational to transactional is worth considering due similar findings in earlier non-CRPS literature (Strunin & Boden, 2004).

Information and Knowledge Needs Are Unmet. People living with CRPS often feel uninformed regarding their condition. Two studies identified that people living with CRPS have limited access to accurate and comprehensive information (Grieve et al., 2016; Johnston-Devin et al., 2021). The ‘Facing the unknown’ theme in Grieve et al. (2016) draws parallels to ‘Dealing with an Unknown Enemy’ in Johnston-Devin et al. (2021), highlighting the lack of information after diagnosis. Grieve et al. (2016) suggested that people were often only provided with verbal information, at times only being provided with the name ‘CRPS’. The consequence of the lack of information is that people will search for their own explanations, including seeking untrustworthy and inaccurate information. Antunovich et al. (2021) noted that when people could not find coherent explanation, they came up with their own explanations: “She believed the bones inside her leg and foot had been burnt” (p. 3016). Beales et al. (2021) found that many searched on the internet, commenting this was often confronting and inaccurate. In a select few studies, the information was adequate (Johannesson et al., 2023; Rodham et al., 2012), but in both studies, the participants had recently completed a specialist inpatient programme with experienced providers.

Additionally, several studies emphasised the desire to be better informed. Two studies identified the gap in desire and perceived knowledge of CRPS (Grieve et al., 2016; Griffiths et al., 2023a). In the appropriately named study ‘What I Needed was the Truth’ by Grieve et al. (2016), participants advised they wanted access to honest and accurate information. Participant Helen emphasised the need to become an expert to not rely on unhelpful healthcare providers: “Yeah, well, I decided that, especially as most of the healthcare professionals I have met don’t even know about the condition, that if I was going to achieve anything, then I needed to be the expert” (p. 19). According to Griffiths et al. (2023a), people wanted information related to the nature and prognosis of CRPS. Greater knowledge about their diagnosis might support them in making informed decisions about treatments: “If it’s something I just need to learn how to deal with, then... I need to, either with their [healthcare providers’] help or without it, figure it out” (Robyn) (p. 1357). Although the inclusion criteria in Griffiths et al. (2023a) sampled a more acute population (7-26 months), the desire to be better informed corresponded to those living with long-term CRPS in Grieve et al. (2016). Two further studies determined that ‘Making Sense of CRPS’ (Beales et al., 2021) and ‘Becoming Informed’ (Rodham et al., 2013) were key themes to living with CRPS but did not elaborate on means to become more informed. In all cases, knowledge was difficult to find but deemed a necessary step to living with CRPS.

Experiences of Diagnosis and Treatment Are Mixed. Most studies showcased the contrast between helpful and unhelpful experiences of healthcare. Most commonly, the lack of experience in local providers was deemed a barrier to coping with CRPS (Rodham et al., 2013). Inexperienced healthcare professionals often provide confusing, contradictory messages, in turn creating negative psychological responses to the condition (Johnston-Devin et al., 2021). Rodham et al. (2012) explored peoples experiences of transitioning home after a specialist pain management programme noting that their local healthcare was a ‘complete and utter waste of time’ (Fiona) (p. 1157). Grieve et al. (2016) found that many people often avoided accessing local providers due to fears of stigmatisation: “You just don’t feel like you can tell anyone because you think they will say you are a psychiatric patient” (Helen) (p. 19). Additionally, delays in diagnosis were often attributed to these inexperienced providers contributing to a fractured relationship to local healthcare: “I find in this day and age it's pretty depressing that it takes a year to get a diagnosis. And, you know, there are kind of quite early indicators that professionals should be able to spot with this condition” (Sarah) (Johnston-Devin et al., 2021, p. 1117). According to Raja et al. (2021), the largest unmet need in healthcare for people with CRPS was delay or incorrect diagnosis. The participants in Griffiths et al. (2023a) attributed delays due to healthcare professionals not wanting to diagnose them. Participant Kimberley articulated the theme ‘Kept in the dark’ when saying, “I just felt like everybody else knew but they wanted to keep me in the dark like a mushroom” (p. 1357). Many of the authors concluded delays or incorrect diagnoses obstruct access to evidence-based care, possibly contributing to worse health outcomes.

Conversely, many studies described the features in their healthcare professionals that fostered a positive therapeutic relationship. People desired someone with experience (Beales et al., 2021; Raja et al., 2021; Rodham et al., 2013); who assessed the whole person, not the condition (Griffiths et al., 2023a); who provided honest and simple language explanations (Beales et al., 2021; Grieve et al., 2016; Griffiths et al., 2023a); demonstrated empathy, listening and understanding (Beales et al., 2021; Griffiths et al., 2023a; Raja et al., 2021); and worked as a team (Raja et al., 2021). Two studies specifically explored the impact of a specialist facility (Johannesson et al., 2023; Rodham et al., 2012) on participant experience. In these cases, accessing healthcare through a speciality centre was seen as a turning point in the journey with CRPS (Rodham et al., 2012). Specialty services offered clear, consistent information that reduced pain-related fear (Johannesson et al., 2023) and validated people's experience of CRPS (Rodham et al., 2012). The contrast between local and speciality services was conveyed by participant Jane when saying, "But medically wise, I felt somebody believed me. It helped me realise it wasn't all in my head" (Rodham et al., 2012, p. 1159). However, it should be noted that momentum gained through specialist inpatient services was difficult to maintain after discharge (Rodham et al., 2012). The theme 'Distance from the pool of expertise' in Rodham et al. (2012) emphasised the challenges people faced after discharge from a supported pain management programme. Generally, the perceptions of healthcare were poor with many reporting unhelpful local services. In a small fraction of cases, experiences of diagnosis and treatment were perceived as positive but it should be noted these cases were participants accessing speciality services. Such services are not commonplace internationally and typically only available for a small percentage of people living with CRPS.

Coping. Concepts of how people managed to cope with CRPS were commonly discussed but rarely featured in the selected studies. One study, 'Coping with Chronic CRPS,' was the only study to exclusively feature coping (Rodham et al., 2013). The authors used an advice-from-patients-to-patients model, concluding the concept of control was central to living with the condition. (Re)taking control was the product of acceptance, gaining the 'right' support, and becoming informed (Rodham et al., 2013). The following paragraphs will outline the areas of acceptance, gaining support and the personal characteristics of coping seen in the literature review.

Several other studies supported the necessity of acceptance for coping with CRPS. Beales et al. (2021) described acceptance as a 'journey' intricately linked to the pursuit of a cure: "they needed to accept their status and adapt to manage the condition (rather than continuing the search for the allusive cure)" (p. 401). Some studies described acceptance as a form of resignation using the description of 'coming to terms with the fact your body can do less' (Johnston-Devin et al., 2021) or ‘giving up the fight’ (Kwon & Kim, 2021). For those who attended specialist pain management programmes, acceptance was more positive, defined as the desire to move forward (Rodham et al., 2012) living life in line with values (Johannesson et al., 2023), whilst accepting the fact there is no cure for chronic CRPS (Rodham et al., 2013). Almost all the authors noted that acceptance appears necessary for coping and is concerned with living a normal life; however, the definition and application of how acceptance supports one to live well was difficult for both participants and authors to articulate.

Gaining the right type of support was a common facilitator of coping across most studies. (Rodham et al., 2013) described the right type of support as someone who could “understand CRPS and be able to empathise with the challenges that accompany living with a chronic illness” (p. 36). The authors described these features in healthcare professionals, social relationships and CRPS networks. As documented in the ‘Experiences of diagnosis and treatment’ section, healthcare professionals who were experienced, viewed the person not the condition, good communicators, actively listened and demonstrated provided more positive experiences of healthcare (Beales et al., 2021; Grieve et al., 2016; Griffiths et al., 2023a; Raja et al., 2021; Rodham et al., 2013).

Those navigating changes in their social roles and intimate relationships described an acceptance by adjusting to a new level of function (Packham et al., 2020). Packham et al. (2020) suggested that people renegotiate intimate roles in order to preserve or reinvent their intimacy. This includes reframing intimacy broader than sexuality, changing intimate behaviours and emotional connection to sex: “If your husband can’t hug you, it is pretty hard to have intimacy. We have had to find other ways to do it” (Apple) (p. 243). The authors suggest developing positive adaptations, such as self-preservation, to foster healthy relationships in couples with CRPS.

Some studies explored the social benefits of talking to others with CRPS. Meeting others with CRPS was validating and beneficial when seeking advice on treatment recommendations: “I think the nice thing is you go in there and everybody gets it, you know. If you’re having a bad day, they all get it, they know what it’s like” (P03F) (Beales et al., 2021, p. 400); “Different stories about what they have done, and how they cope with it. Cos I’ve tried their ways and even if it hasn’t worked, I’ve given it a go” (Crystal) (Rodham et al., 2013, p. 34). Meeting others in a group also gave some individuals a sense of community in a life that was lonely and isolating: “Getting to know people, really making friends who understand exactly how you feel or you can share experiences and things like that. Tips and ideas for each other. I think that was really the most beneficial” (participant #5) (Johannesson et al., 2023, p. 5). Finding other people with a similar shared experience gave not only validation but motivation many of them could cope and manage with the condition.

A few studies discussed the personal characteristics of people who were seen to be coping with CRPS. The concept of resilience and self-coherence was alluded to by Griffiths et al. (2023a) in the theme ‘Trying not to let it stop me.’ The authors noted that people usually engaged with healthcare with the desire to return to the person they once were: “I wanted to get back to being the person I was before the injury… getting back to work, being able to go out in my garden and not pace myself” (Joan) (p.1357). More resilient participants lived their life by a process of ‘working around it’ or ‘ignoring it’ demonstrated strong sense of self-coherence and adaptability in the face of adverse experiences. Raja et al. (2021) found that people reported coping with CRPS by either not yielding to CRPS or being driven by a sense of purpose and self-worth. The concept of ‘not giving in’ and confronting problems was also shared by Johnston-Devin et al. (2021) who described types of problem-solving, including adapting self-care, doing online shopping, and making ready-made meals. For the final theme, ‘Warrior or Prisoner of War,’ Johnston-Devin et al. (2021) eloquently described the decision to either be defined by an altered vulnerable body or rise to the challenges presented. Although these strength-based features were sparsely discussed in the literature, they appear highly pertinent to individuals who want to live well with CRPS. Whether these features are innate characteristics of people who cope or learned through professional support and experimentation remains to be determined.

Implications of Lived Experience Literature on Living Well With CRPS

The lived experience or patient perspective remains underrepresented in the wide breadth of CRPS literature. The above findings suggest that living with CRPS presents both physical and emotional challenges that negatively impact one's personal and social identities including the alteration of one's self-concept. People living with CRPS want to be better informed, but information is difficult to find, with much of the information inaccurate and misleading. To make matters worse, experiences of diagnosis and treatment are disappointing unless seen through specialty services, although this only applies to a small percentage of people.

Only a small fraction of the available lived experience literature describes aspects of coping with CRPS. Most commonly, authors discussed acceptance and coming to terms with their new levels of function, renegotiating intimate roles with adaptations and self-preservation, and finding social connections with other people living with CRPS. Most studies described the characteristics of participants that were seen to be coping with CRPS without exclusively featuring them. Characteristics of resilience, self-coherence, and pragmatic problem-solving were common across studies with people describing coping and self-management.

With respect to methodological quality of research, most of the studies demonstrated varying strengths and weaknesses, as detailed in Tables 2 and 3 (see page 21–24). Most commonly, studies failed to either state theoretical frameworks or did not demonstrate robust recruitment, data collection or data analysis by failing to adhere to methodological rigour (Antunovich et al., 2021; Johannesson et al., 2023; Johnston-Devin et al., 2021; Packham et al., 2020; Raja et al., 2021). Although many of these studies adopted reflexive thematic analysis methods, whereby researcher subjectivity is a resource, the lack of transparent adoption of theoretical, methodological and analytic choices means the study dependability is limited (Koch, 2006). Additionally, two studies did not critically identify their role as researchers (Grieve et al., 2016; Kwon & Kim, 2021) and two did not identify relationship to the participants (Rodham et al., 2012; Rodham et al., 2013). According to Koch (2006), the credibility of research is enhanced when researchers describe and interpret their own experiences. Therefore, the lack of reflexivity on the researcher’s part means the credibility of these findings should be considered when assessing their transferability.

All included studies represented a wide and varying range of participants' characteristics. Of note, this included upper and lower limb CRPS, type-I and type-II, acute and long-term, treatment-naïve and treatment-resistant, with varying levels of confounders such as co-morbidities. Often, heterogeneity is seen as something that reduces the transferability of research into clinical practice with conventional research methods that try to control for every factor to produce ‘clean’ data (Denzin & Lincoln, 2018). However, it can be argued that as CRPS is a low-frequency condition, any research is going to be ‘messy.’ Recruitment will, therefore, also be extremely heterogeneous in terms of time of onset, body site, intensity, demographics and other co-morbidities. Additionally, by the time individuals receive a diagnosis, they have been through multiple treatments and, by definition, have more severe symptoms and their condition may be more treatment-resistant. Some authors argue that greater diagnostic clarity, notably subgrouping, may provide more research with an option for greater homogeneity in studies (Ferraro et al., 2024). However, for now, the diverse, widespread and heterogenous nature of CRPS represents the ‘real world’ of pain management for this condition. Nonetheless, research still needs to be rigorous enough to be valid; as such, there are certain methodological issues that should be taken into account when interpreting the findings in the literature review above.

This qualitative research synthesis has shown that the finer details of patient narratives, storytelling and sensemaking are vital, yet vastly underrepresented in the wider CRPS research landscape. Compared to the quantitively orientated studies, there is very limited research featuring the voices of those living with the condition. What is the most striking is the lack of strength-based studies and demonstration of successful approaches people have adapted to live with CRPS. Only a limited number of studies have explored strength-based measures for people living with CRPS. In these studies, higher quality of life was related to resilience (Bodde et al., 2014; Wertli et al., 2023), pain acceptance (Cho et al., 2013), and the use of active coping strategies in self-management (Marinus et al., 2013). Interestingly, the international guidelines for core outcomes in CRPS research do not recommend any assessments of psychological strengths (Grieve et al., 2017). Therefore, much of the research focusses on reducing symptoms and psychological deficits such as anxiety, depression, catastrophising, rather than psychological strengths such as resilience, optimism, active coping.

As discussed at the start of this chapter, CRPS is a highly variable condition, and some people live meaningful lives despite the condition. However, almost all of the available research focusses on the difficulties of living with CRPS and the shortcomings of healthcare and society. Understandably, this subset of people are the ones who are more likely to require ongoing support and thus feature more frequently in research. However, by reframing our approach to research to include those living well, their contribution can be seen as an untapped resource, offering new and novel self-management ideas that escape the clinical trials and conventional healthcare models. These findings are likely to be transferrable to those ‘not living well.’ Yet nothing is known about this group of people. Therefore, to begin to build a model of living well with CRPS, the next section will feature a brief, targeted literature review exploring the current models of living well with chronic pain and illness.

Living Well With Chronic Illness

The concept of living well has been documented in both chronic pain and chronic illness literature. In the following section, I describe a targeted literature search to find relevant theories and models of living well with chronic pain and illness to support the current study. Using the search strategy in the literature review, the following terms were added: “Chronic pain” OR “Persistent pain” OR “Chronic illness” AND “Living well.” The following is a brief review:

Living Well: A Definition

‘Living well’ will mean different things depending on the context in which it is viewed. Within the chronic pain literature, Lennox Thompson (2015) defined living well as “people who believe they are ‘in control’, and for whom life goals and occupations are the primary focus rather than their chronic pain” (p. 19). Similarly, Richardson et al. (2015) defined living well with chronic pain in older age was not a matter of limited interference; instead, being physically and socially active within one's capabilities. In those with life-limiting co-morbidities such as chronic kidney disease, cancer and HIV, living well was defined as life participation and the ability to do meaningful activities (Bruce et al., 2014; Friedman & Ryff, 2012; Kalantar-Zadeh et al., 2021). In end-of-life care, living well was moving towards living life rather than living illness (Arantzamendi et al., 2020). Therefore, living well appears to be related to maximising aspects of life rather than minimising the impact of illness. The living well literature often uses terminology interchangeably when describing those who identify as living well. Commonly, *coping*, *resilience, self-coherence,* and *acceptance* are terms used to describe the characteristics of individuals living well but do not act as definitions of the meaning of living well.

Coping may be one aspect of living well, but it does not fully encompass living well. Coping with chronic pain refers to the cognitive and behavioural actions that are used to adapt or manage the negative responses of pain (Tunks & Bellissimo, 1988). Coping and coping strategies have been commonly taught principles in pain management programmes for decades (Jensen et al., 1991). Those who use coping strategies to manage their chronic pain have demonstrated less overall distress (Jensen et al., 1991). According to Lennox Thompson (2015), living well sits on the spectrum of coping with chronic pain. On one end, 'not coping' has high distress and disability, whilst on the opposite end, 'living well' includes minimal distress and disability. Coping, therefore, sits somewhere between 'not coping' and 'living well' (Lennox Thompson, 2015). Coping is the deliberate attempt to reduce distress, yet the absence of distress *does not necessarily indicate* whether someone is thriving (Nutbeam & Muscat, 2021). Therefore, coping may be one aspect of living well, but coping is not synonymous with living well.

Acceptance may be a prerequisite to living well. In the context of chronic pain, acceptance commonly refers to the willingness to experience pain without attempting to control it while aligning actions toward personally meaningful purposes (Hayes et al., 2006). Acceptance is often described as 'moving on' in the context of cancer and lifelong illness (Arantzamendi et al., 2020; Robinson, 2017). Acceptance differs from traditional pain-related coping, where coping attempts to control or manage distressing experiences, and acceptance does not (Vowles & McCracken, 2008). Greater pain acceptance has been linked to less distress and disability while improving physical performance in chronic pain (Vowles & McCracken, 2008). Therefore, acceptance may be a precondition to living well, where individuals are more likely to invest in controlling their lives rather than controlling their illnesses.

Resilience may be a feature of those who can live well in the face of chronic illness. Resilience is defined as the process and skills someone applies within the face of adversity (Luthar et al., 2000). Several chronic pain studies have linked resilience to improved physical functioning (Sheedy et al., 2017), positive coping (Karoly & Ruehlman, 2006) and decreased distress and catastrophising (Ong et al., 2010). Resilience measures have predicted better outcomes following functional restoration programmes (France et al., 2020) and improved return to work for those with chronic pain (Wainwright et al., 2019). Resilience includes not only the features of coping but encompasses the broader personal attributes, transactional processes and outcome of experiences through life (Karoly & Ruehlman, 2006). Resilient individuals tend to draw on positive problem-solving skills, be optimistic, manage setbacks well, and have a greater sense of purpose and meaning in their lives (Sturgeon & Zautra, 2013). Therefore, resilient individuals may be more likely to succeed in their pursuit of living well due to their resourcefulness and pragmatic approach to living alongside chronic conditions.

A *Sense of coherence* may facilitate the processes of living well with chronic illness. Sense of coherence is an individual's ability to modify their lifestyle to maintain physical and emotional health despite stressors (Antonovsky, 1996). A low level of sense of coherence has been linked to higher depression, higher pain rates, and poorer levels of functioning in people with chronic pain (Aguilar-Latorre et al., 2023). Additionally, returning self-coherence has previously been connected to those living well with chronic pain (Lennox Thompson et al., 2020). Therefore, a strong sense of coherence may give individuals the confidence and necessary tools to modify their journey towards living well with chronic illness.

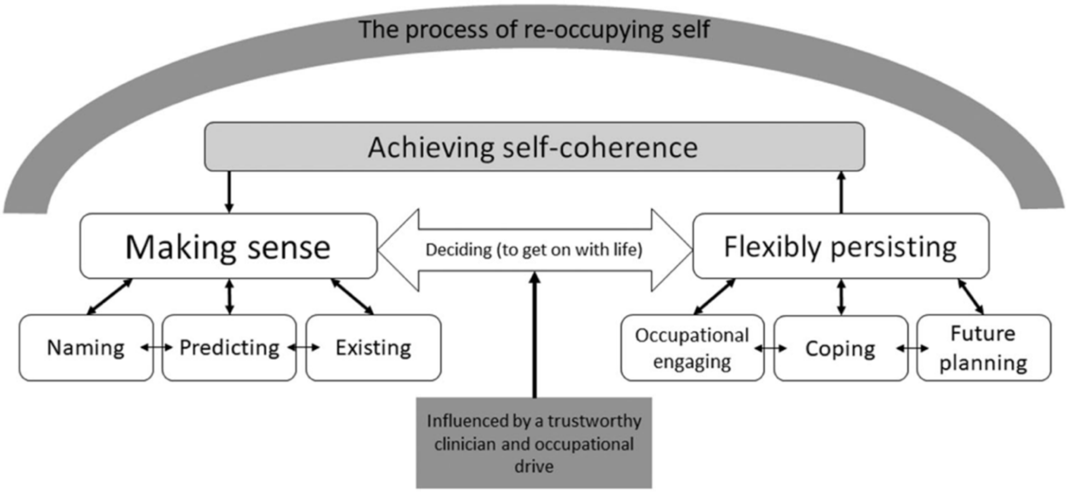
Summarising a complex concept like 'living well' is difficult through contrasting definitions. The following section identifies three models that explain how individuals can live well with chronic pain and illness. There is a substantial body of evidence detailing these models, including different derivations for chronic conditions. I will briefly outline each model and discuss their relevance to my findings in the Discussion.

Models of Living Well

Living Well and Re-Occupying Self (Lennox Thompson et al., 2020). The model developed by Lennox Thompson et al. (2020) proposed that living well with chronic pain was achieved through the process of reoccupying one's sense of self. Their self-concept was renegotiated by achieving self-coherence. Lennox Thompson suggests people achieve self-coherence through a sequential process of making sense of chronic pain, deciding to turn from patient to person, and maintaining through flexibly persisting (See Figure 1). The model parallels the present CRPS literature review findings, describing preconditions of achieving self-coherence as sensemaking, finding the right clinician, and persisting. Lennox-Thompson suggests this process explains how individuals can accept chronic pain as a part of their life and reframe the necessary adjustment within a renegotiation of their self-concept.

Figure 1

Conceptual Diagram of the Process of Re-Occupying Self

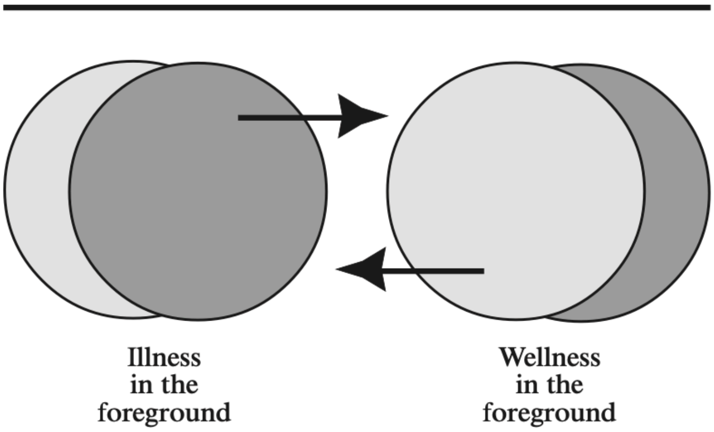


From "Living well with chronic pain: a classical grounded theory," by B. Lennox-Thompson et al., 2020, *Disability and Rehabilitation, 42*(8), 1141-1152. https://doi.org/10.1080/09638288.2018.1517195

The Shifting Perspectives Model of Chronic Illness (Paterson, 2001). The model proposed by Barbara Paterson (2001) describes living with chronic illness as a continually shifting process between wellness-in-the-foreground and illness-in-the-foreground. Paterson argues that the terms 'acceptance' and 'denial' do not have meaning for those living with chronic illness. For example, people may hold their chronic pain in the foreground to adapt to constraints and find balance in life. Many healthcare professionals would consider this 'acceptance,' a positive adaptation. In contrast, people may hold the burden of their condition in the background to live as they desire. Conversely, many healthcare professionals would deem this 'denial' and consider it maladaptive. Paterson argues that neither is right nor wrong; rather, the impact of chronic illness shifts depending on the context. This model may become relevant when describing how individuals may live meaningful lives but retain hope for a cure. Paterson suggests that living with chronic illness is not linear rather ever shifting.

Figure 2

The Shifting Perspectives Model of Chronic Illness

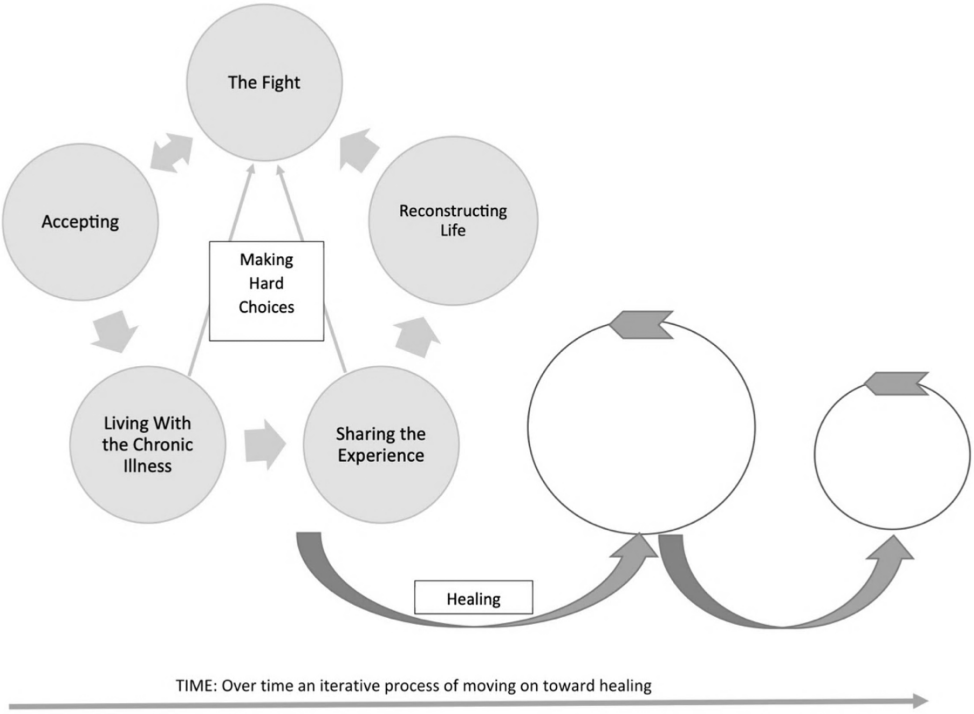


From "The shifting perspectives model of chronic illness," by B. L. Paterson, 2001, *Journal of Nursing Scholarship, 33*(1), 21-26. https://doi.org/10.1111/j.1547-5069.2001.00021.x

The Healing Process of Moving On (Robinson, 2017). The model developed by Carole Robinson (2017), depicts the healing process of 'moving on' as an iterative process consisting of five interconnected phases. The phases include 'The Fight,' 'Accepting,' 'Living with the Chronic Illness,' 'Sharing the Experience,' and 'Reconstructing Life.' Robinson's model differs from Paterson's (2001), whereby the cycle is iterative, moving in a linear direction over time, lessening as people live well alongside chronic illness. The repeating cycles illustrate the iterative nature which is lessened overtime. Arantzamendi et al. (2020) adapted the model to those living with advanced cancer, noting that 'moving on' was the shift in focussing on 'living' whilst there was the awareness of dying. This formed the idea that living well was about living a life rather than living an illness (Arantzamendi et al., 2020). Both Robinson (2017) Arantzamendi et al. (2020) models of 'moving on' strongly support the definitions of acceptance in the CRPS literature review. The iterative nature and the notion of living alongside illness may share features with those who are living well with CRPS.

Figure 3

The Healing Process of Moving On



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Implications of Living Well With Chronic Illness

After reviewing the living well with chronic illness literature, one can see that the concept of living well with long-term and life-limiting illness is reasonably common. These strength-based narratives are a contrast compared to the deficit-focused CRPS literature. The aforementioned targeted literature, although brief, highlights a substantial evidence base related to living well with chronic pain, mental health, diabetes, chronic obstructive pulmonary disease, kidney disease and HIV to name just a few. This literature suggests that individuals who are living well with chronic pain are more resilient (Sheedy et al., 2017; Sturgeon & Zautra, 2010), have a strong self-concept (Lennox Thompson et al., 2020; Richardson et al., 2015), and feel empowered to self-manage (Lennox Thompson et al., 2020; Toye et al., 2021).

Using the living well with chronic illness literature we can make some assumptions about individuals who may be living well with CRPS:

- They may be coping with their CRPS symptoms and therefore consider themselves to be living well with CRPS.
- They may use coping strategies which may include techniques to moderate symptoms but also techniques to support them to live well.
- They may be actively self-managing and not passive recipients of healthcare.
- They may be more accepting of their situation which permits them to focus on living life rather than living a condition.
- They may be more resilient, pragmatic problem solvers using tools in the face of adversity.
- They may have a strong sense of coherence where they can confidently modify their lifestyle despite stressors.
- They may more easily negotiate their self-concept which motivates their journey to living well.

The featured living well models illustrate the idea of living life and not living an illness. Each of these models differs somewhat in terms of specifics but draws on commonalities related to strengthening self-coherence, accepting, and shifting of emphasis between illness and wellness. Whilst striving to seek these features, in theory, improves the quality of life and reduces the impact of pain for those living with CRPS, more research is needed to determine whether the findings of living well in other chronic pain are generalisable to CRPS.

Study Rationale and Research Questions

At present, there is no research that explores people who self-identify as living well with CRPS. Current evidence suggests that some people maintain meaningful lives despite CRPS, but others do not. This study aimed to understand the process of living well with CRPS from the lived experience perspective. I believe that understanding this process will better inform treatment and find a path forward for those living with CRPS. The next chapter will outline the methodology and methods applied to answer the following research questions:

1. What is living well with CRPS?
2. What processes were necessary to get to a point of living well with CRPS?

Chapter Two Summary

This chapter summarised the evidence and contemporary problems related to the clinical presentation, epidemiology, proposed mechanisms, diagnosis, and management of CRPS. Following this, an in-depth qualitative synthesis of the limited body of literature on living with CRPS was presented. The final section summarised the current literature on living well with chronic illness, identifying some of the assumptions taken to build a study on living well with CRPS.

Chapter Three: Methodology and Methods

This chapter outlines the methodological considerations and methods that underpin this study. As a part of reflexivity, the chapter begins by explaining my position as a researcher and healthcare professional undertaking this qualitative inquiry. Reflecting on my philosophical stance of interpretivism, I detail the application of reflexive thematic analysis as a method in the co-construction of knowledge. The methods section will outline the ethical considerations taken followed by the detailing and justification for sampling, recruitment, data collection and data analysis. The final section will outline the steps taken towards quality in this reflexive thematic analysis.

Methodology

Researcher Positionality: Reflexivity and Subjectivity as a Resource

> *Reflexive TA approaches embrace researcher subjectivity as a resource for research, view the practice of TA as inherently subjective, emphasize researcher reflexivity, and reject the notion that coding can ever be accurate.* (Braun & Clarke, 2023, p. 2)

Qualitative inquiry is often an interpretative practice aiming to construct the nature of reality for participants (Denzin & Lincoln, 2018). Interpretative practices co-construct the meaning of reality between the researcher and participant; thus, what the researcher brings to the enquiry is an important resource within qualitative inquiry (Braun & Clarke, 2021b; Gough & Madill, 2012). The process of acknowledging subjectivity through critical reflection on oneself as the researcher is known as reflexivity (Denzin & Lincoln, 2018). Reflexivity is then communicated through positionality, reflecting not only values and assumptions but experiences, disciplinary traditions, ideologies and sociocultural influences that shape the interpretation of the data (Denzin & Lincoln, 2018; Finlay, 2003). In the next section, I provide a reflexivity statement, identifying my position within the area of research and acknowledging the role subjectivity takes in my methods and analysis. The content of this section is from an interview with my primary supervisor (DB) and myself on the 16th of August, 2022.

Positionality Statement

I am Tim McVicar, a New Zealand-based physiotherapist working in a tertiary pain management service in Auckland, New Zealand. I completed my undergraduate physiotherapy degree at Otago University in 2011 and have spent the majority of my career working in musculoskeletal healthcare and chronic pain management. I have been fortunate enough to work in pain management services across New Zealand and the UK, seeing a wide range of cultures and their approaches to living well with chronic pain.

As discussed in the '*My professional journey with CRPS'* section (see page 5), I approach this topic of CRPS as an 'outsider' (Hayfield & Huxley, 2015). I do not live with CRPS nor any chronic health condition. I have to acknowledge my privilege as a New Zealand European cis male. I have not, that I am aware of, faced discrimination based on my culture and context. My professional journey has allowed me to gain an understanding and empathy of living with CRPS but I acknowledge that my position has limitations in constructing knowledge about the lived experience of CRPS. I felt it was important to ensure the resonance, appropriateness and sensitivity of this research topic, so I approached someone living with CRPS to guide my process. Katy Rossiter acted as an expert patient in an advisory position, helping to co-construct the recruitment leaflet, interview questions and theme generation. So, as a physiotherapist, moulded by my experiences above, I wanted to begin by honouring the individual voices and their experiences while acknowledging that I am filtering my understanding through the lens of an experienced physiotherapist practitioner.

By profession, I am a physiotherapist; however, my experience working in pain management services has challenged my disciplinary assumptions on pain and disability. My view of pain, which I detail in the next section, recognises that pain is a complex emergent phenomenon influenced by sociocultural and psychological factors. I recognise this challenges the reductive biophysical approaches seen by much of my profession. I don't discredit the role of biophysical factors; rather, I emphasise the role of one's thoughts, beliefs and emotions within their wider social context alongside these physical factors. I therefore believe CRPS requires a socio-psycho-bio approach to management and living well. In the introduction, I identified the assumptions I bring to this research study:

- *Assumption #1: People living with chronic pain are not understood and are poorly supported by our current biomedical frameworks in healthcare.*
- *Assumption #2: People living with chronic pain often aren't seeking pain elimination but rather the rebuilding of their lives alongside pain.*
- *Assumption #3: People living with CRPS are experts in their self-management. We should use their experiences as a resource in collaborative healthcare.*
- *Assumption #4: Living well with CRPS is subjective and independent of disease severity.*

I acknowledge that my assumptions will influence my interpretation and sensemaking of the data. I encourage the reader to use this transparency to view subjectivity as a resource rather than a limitation.

I would like also to state that I am a novice researcher. This will be my first attempt at conducting qualitative research. Reflexive thematic analysis within an interpretivist paradigm acknowledges researcher subjectivity in the co-construction of meaning (Braun & Clarke, 2021b). However, I have needed support in the co-construction from two experienced researchers (DB/BLT)— one in the research field of CRPS and the other in qualitative methodologies in chronic pain. Braun and Clarke (2021b) emphasise embedding reflexivity throughout the analytical process; therefore, I maintained a reflexivity journal, making notes following participant interviews. I also scheduled regular meetings with my research supervisors, which offered reflexive questioning of my assumptions about the data. The following section will further outline my interpretivist philosophical stance.

Interpretivist Philosophical Paradigms in Qualitative Inquiry

Most qualitative inquiry aims to make sense of or interpret phenomena through the meaning people bring to them (Denzin & Lincoln, 2018). Interpretivism focusses on the individuals' perceptions to make sense of subjective and socially constructed phenomena (Flick, 2018). Unlike constructivism, a similar relativist ontological paradigm based on the co-construction of meaning, interpretivism recognises the role of researcher reflexivity but highlights the participant's voice and the meaning they attach to their lived experiences (Walt, 2020). The focus remains on understanding their social world rather than influencing change through making meaning (Flick, 2018).

These relativist ontological approaches differ from positivist philosophies, which distance the researcher, aiming to seek a single objective truth (Denzin & Lincoln, 2018). Interpretivist philosophical paradigms, with subjectivist epistemology, reject this view, noting that it is impossible to explore lived experience by assuming individuals live within a stable, unchanging environment that is free of discourse and culture (Finlay, 2003; Flick, 2018). Positivist philosophies imply there is a singular truth for an experience, available and waiting for the researcher to uncover. This is the fundamental distinction between realism and relativism (ontology) and objectivism and subjectivism (epistemology). I argue that it is impossible to understand and predict social behaviour from 'natural science' methods; therefore, my philosophical stance of interpretivism is the pragmatic approach to making sense of the phenomena of living well.

A belief I bring to this research is that pain is a subjective experience influenced by a combination of biological, psychological and social influences. I do not view pain as an objective and measurable phenomenon. Waddell (1987) argued that pain cannot be evaluated without understanding the person who is experiencing nociception. Others, therefore, postulate that understanding someone's perception of pain requires their understanding of illness, interrelationships, psychological status and sociocultural context (Engel, 1977; Gatchel et al., 2007). Moreover, the construct of 'living well' by its very nature is subjective and defined differently by each individual. Therefore I believe that adopting a positivist stance toward this research question does not allow for exploring the 'understanding and meaning of living well.' Adopting an interpretivist philosophical paradigm supports the understanding and interpreting of living well with CRPS from the perspectives of those living with the condition.

Reflexive Thematic Analysis

The Context of Reflexive Thematic Analysis

Thematic analysis is a method of analysing qualitative data by developing patterns of meaning across a data set (Braun & Clarke, 2021b). Patterns are generated through coding practice and theme development (Braun & Clarke, 2021b). Thematic analysis shares similarities in identifying patterns with other qualitative methodologies, such as grounded theory (Charmaz, 2006) and interpretative phenomenological analysis (IPA) (Smith et al., 2009). Thematic analysis draws on aspects of phenomenology through exploration of phenomena yet does not seek to define the essence of phenomenology as in IPA, nor produce a theory as in grounded theory. Thematic analysis is therefore considered a flexible method, utilised within clearly defined philosophical paradigms, rather than a fully embedded stand-alone methodology (Braun & Clarke, 2021b).

Reflexive thematic analysis, one form of thematic analysis, was reconceptualised by Virginia Braun and Victoria Clarke to recognise the value of researcher subjectivity as the analytical resources via reflexive engagement with the data (Braun & Clarke, 2021b). Building on their earlier method (Braun & Clarke, 2006), Braun and Clarke wanted to develop a theoretically flexible method grounded in the assumptions and values of qualitative research. The Braun and Clarke (2021b) thematic analysis differs from other types of thematic analysis that adopt systematic approaches to coding, for example, using multiple coders to ensure 'inter-rater reliability' (Boyatzis, 1998; Guest et al., 2012). Braun and Clarke (2021b) argue that these methods are essentially positivist, missing the spirit of qualitative research, that humans are subjective sensemaking beings. Braun and Clarke use the Kidder and Fine (1987) distinction of 'Big Q' and 'small q' qualitative research. 'Big Q' qualitative research uses qualitative techniques and is underpinned by qualitative philosophical values. ‘Big Q’ recognises that humans are subjective sensemaking beings, who live in social and complex worlds. In contrast, ‘small q’ qualitative research combines qualitative and quantitative techniques, concerned with accuracy and reliability. Braun and Clarke (2021b) argue that this contradicts the spirit of qualitative philosophical values and assumes there is a single truth waiting to be discovered through coding.

The Use of Reflexive Thematic Analysis in Living Well With CRPS

This research aims to explore participants' lived experiences and sensemaking approaches to living well with CRPS. This was conducted through in-depth interviews using researcher subjectivity and reflexivity to guide the interpretation of data through an inductive analysis. As all research methods are imperfect, adopting a stance with an interpretivist approach will honour the otherwise neglected voice of those experiencing this subjective experience we call pain. Reflexive thematic analysis allows a flexible method aligning with qualitative paradigmatic and interpretivist epistemological assumptions (Braun & Clarke, 2021b). Reflexive thematic analysis is a good fit for the purpose, allowing patterns to be drawn across the data set and aligning with the interpretivist paradigm due to its theoretical flexibility (Braun & Clarke, 2021b). The most recent derivation of reflexive thematic analysis by Braun and Clarke (2021b) was followed to ensure sufficient engagement with the data and upholding the spirit of ‘Big Q’. This included the following phases; *familiarisation, coding, generating initial themes, developing and reviewing themes, defining and naming themes,* and *writing* (Braun & Clarke, 2021b).

Methods

Ethical Considerations

The study received ethical approval from Auckland University of Technology Ethics Committee (AUTEC) on 14/06/2022 under approval number 22/119. Copies of the approval form are attached in Appendix A. The research was undertaken in accordance with the Auckland University of Technology Code of Conduct for Research.

Voluntary Participation. All participants were offered the choice to participate in the study without coercion or pressure. They were advised that the decision to participate was voluntary (their choice) and that they would not be disadvantaged by it. They were also offered the opportunity to withdraw from the study anytime during the data collection phase. They were provided with this information in the study information sheet attached in Appendix B.

Avoidance of Harm. Talking about aspects of diagnosis, medical interventions, and negative experiences of healthcare may be distressing for some. To minimise potential distress to participants, I conducted all interviews sensitively, using my experience as a senior physiotherapist working in chronic pain. AUT Student Counselling and Mental Health offered three free sessions of confidential counselling support for participants if required. These sessions were available for issues arising directly from participation in the research and not for other general counselling needs. This information was also available in the study information sheet attached in Appendix B.

Informed Consent. Participants were informed of the broad nature of topics to be discussed and were asked to consent through all data collection stages. Written consent was obtained for data collection and the outcomes of data analysis. Participants were informed of their right to withdraw their data at any time during the data collection before the commencement of analysis. Participants were offered a copy of the analysis, but member checking was not sought as this is not a feature of reflexive thematic analysis (Braun & Clarke, 2021b). Copies of the consent form and oral consent protocol for videoconference interview are attached in Appendix C.

Privacy and Confidentiality. Anonymity was achieved through a pseudonym of the participants' choice. I removed any quotes with potentially identifiable details during transcription and data analysis. Additionally, confidentiality was upheld as I, the primary researcher, was the only member of the team who interacted with the participants. The research supervisors had access to anonymised transcripts devoid of identifiers.

Protection of Data. The data collected were classified as sensitive due to the personal nature of the interviews. Interviews were recorded via an iPhone and Zoom and then immediately uploaded to a password-protected folder on AUT's SharePoint after recording. Recordings were then immediately deleted from the recording device. Post-analysis transcription recordings and data were transferred to the primary supervisor (DB) AUT network drive.

Cultural Responsiveness in Aotearoa, New Zealand. Māori or other cultural groups were not directly recruited; however, as this is a New Zealand-based study, I sought the consultation of Te Ara Tika: Guidelines for Māori Research Ethics from Eva Morunga (Te Rarawa/Nga Puhi), Health Psychologist. We discussed the importance of acknowledging a Māori way of being, that is, being tikanga-based, practising manaakitanga, forming relationships with participants, listening to their stories, allowing for comfort breaks, and offering karakia. We discussed recruitment strategies and using social media messaging to "front up" and explain the kaupapa of the research emphasising the purpose of helping people.

The qualitative study design aimed to take a mana-enhancing stance with the participants being acknowledged as experts in the context of their personal narratives. A strength-based approach was advised as a well-designed study to collaborate and engage with Māori. A copy of the Māori Consultation support letter is attached in Appendix D.

Conflict of Interest. All participants were naïve to me (the researcher and interviewer). Participants may have received healthcare services at the organisation where I work; however, this was strictly not discussed with participants. There were no other power imbalances or coercive influences discussed.

All participants were offered a koha (gift) for participating in the study. They were informed that the gift was a $50 voucher only after finishing the interview.

Sampling

Sampling in qualitative inquiry involves selecting a corpus of empirical cases to study a phenomenon (Flick, 2018). Therefore, designing a lived experience study exploring a subgroup of individuals with a rare disease requires a deliberate and selective sampling strategy.

I chose criterion purposive sampling to select individuals who identify as living well with CRPS. According to Patton (2002), purposive sampling is a preferred method for identifying and selecting information-rich cases within a population subset. More specifically, criterion purposive sampling uses specific criteria for inclusion and exclusively examines those individuals (Maxwell, 2012; Patton, 2002).

Locating a subgroup of people who are living well with a rare chronic condition is challenging subgroup to reach. Those who are living well are not commonly seeking healthcare and, therefore, cannot be located with conventional recruitment strategies. Therefore, in addition to criterion purposive sampling, I adopted a combination of network- and snowball purposive sampling. Network purposive sampling occurs through collaboration with colleagues or professionals to identify suitable participants (Patton, 2002). Snowball sampling occurs by asking current participants to identify and refer other appropriate participants for the study (Patton, 2002). I aimed to construct a corpus of a wide range of ages, genders, living statuses, disease severity, and disease time course. I felt it was important to represent the whole living well subset whilst still ensuring we interviewed 10 participants.

Inclusion Criteria

The inclusion criteria were that participants had a diagnosis of CRPS (type I or II), and:

a) were diagnosed more than 12 months ago;
b) report weekly symptoms consistent with CRPS;
c) aged of 18 years and over;
d) able to speak English well enough to participate in an interview study; and
e) self-identify as living well with CRPS.

Rationale for Inclusion Criteria. Participants were asked to self-report if they were formally diagnosed with CRPS (type I or II). As there is no gold-standard test for diagnosing CRPS, a formal diagnosis is made by fulfilling criteria of both self-reported symptoms and physician-observed signs known as the 'Budapest criteria' (Harden et al., 2010b) and the recent derivation 'Valencia criteria' (Goebel et al., 2021). Written proof by way of medical clinic letters was not requested, which is consistent with previous qualitative research (Johnston-Devin et al., 2021; Packham et al., 2020). Participants were then screened using the CRPS Severity Score (Harden et al., 2010a) to ensure they continued to meet the symptom-based section (1 symptom in 3 or more categories) of the Budapest criteria (Harden et al., 2010b). However, in keeping with international standards, observable signs were not verified by physical examination to enable participants to engage in the research remotely (Grieve et al., 2023).

Adopting a diagnostic duration greater than 12 months and continued weekly symptoms ensured that individuals continued to live and manage CRPS rather than those with spontaneous resolution. Additionally, longer duration was likely to promote discussions relating to long-term adaptations rather than short-term, temporary changes. Two earlier CRPS qualitative studies referenced a subset of individuals with 'chronic CRPS' (Brunner et al., 2010; Rodham et al., 2013), representing patients with symptom duration beyond three and six months respectively. However, one systematic review demonstrated that a proportion of patients continued to improve in terms of disease severity and pain intensity up to 13 months (Bean et al., 2014). Therefore, I chose not to adopt the term 'chronic CRPS,' which is not widely used in the IASP terminology, nor is there a consistent consensus on timeframes to determine chronicity.

The choice to limit participants to 18 years and over was due to the different clinical pathway both adolescents and paediatric patients receive within the New Zealand healthcare system. Additionally, strategies and approaches for paediatrics living well with CRPS are likely to differ from adults as their presentation and disease trajectory is often different (Weissmann & Uziel, 2016).

Limiting inclusion to those with fluent English was to ensure the correct interpretation of interview data.

The self-identification of living well with CRPS was deemed sufficient for inclusion. As discussed in the introduction, living well is a subjective phenomenon determined by the individual. As such, no metrics or exclusion were applied to determine whether someone was living well.

Rationale for Exclusion Criteria. All current or past patients of the research team (Tim McVicar, Dr Debbie Bean, Dr Bronwyn Lennox Thompson) were excluded. This was to limit any potential power imbalances during the interview phase and stated within the ethics approval (Appendix A). Previous research participants of the research team were not excluded.

Recruitment

A brief description of the study and a link to the study website were posted on social media (Twitter). An email invitation was also sent to people who participated in a previous New Zealand-based CRPS research study (Bean et al., 2016). Additional recruitment was sought via word of mouth through both participants and healthcare professionals.

This study aimed to recruit 6 to 10 participants. Terry and Hayfield (2021) recommend 6 to 10 participants for a reflexive thematic analysis whereby each participant is likely to make a considerable contribution. The number of participants was a pragmatic decision based on the timeframes for data collection and analysis for a Master's thesis.

If the potential participants met the online eligibility criteria, they were provided with a full copy of the participant information sheet and requested to complete an online consent form. They were provided with an opportunity to have the study explained in depth and ask questions. Following this, they completed an online survey consisting of demographic information and three clinical and psychometric questionnaires commonly used to estimate disability. These measures were used to describe the personal characteristics of people who self-identify as living well. After completing consent and survey information, participants were offered an interview. If they did not provide consent, answered 'no' to any of the screening questions, or did not meet the screening criteria, they were directed to a page thanking them for their interest and explaining they were ineligible to participate.

Data Collection

The primary method of data collection was individual semi-structured interviews. In addition, participants completed the short online survey described above. This included demographic information followed by a set of standardised psychometrically valid and reliable outcome measures. This was used not only for screening but also to characterise the sample.

Participant Characteristics

Demographic, clinical and psychometric questionnaires were selected in line with the 'Recommendations for a first Core Outcome Measurement set for complex regional PAin syndrome Clinical sTudies' (COMPACT) (Grieve et al., 2017). Demographic data included pseudonyms, gender, age, ethnicity, limb affected, disease duration, diagnosis duration, education level, employment, and relationship status. Pain intensity and pain interference were measured using the Brief Pain Inventory short form (BPI) (Cleeland & Ryan, 1994). The BPI is an 11-item patient-reported outcome measure (PROM) that measures pain intensity and severity (4 items) and pain interference (7 items) using an 11-point numerical rating scale (NRS), where 0 = no pain/interference and 10 = severe pain and complete interference (Cleeland & Ryan, 1994). The BPI has demonstrated reliability (Atkinson et al., 2011) and validity (Keller et al., 2004) in chronic non-cancer pain. Disease severity was measured using the self-reported symptom subscale of the CRPS Severity Score (CSS) (Harden et al., 2010a). The CSS is a 17-item PROM, 2-point checklist (yes/no), mirroring the Budapest diagnostic criteria (Harden et al., 2010b). The CSS has demonstrated a high internal consistency between CRPS and non-CRPS conditions (Harden et al., 2010a). The utility of the 8-item self-reported symptom scale has been supported in previous international clinical research recommendations (Grieve et al., 2023). Pain acceptance, which is not part of the COMPACT framework, was measured using the Chronic Pain Acceptance Questionnaire-2 (CPAQ-2) (Vowles et al., 2020). The CPAQ-2 is a 2-item, 6-point scale measuring pain willingness and activity engagement (Vowles et al., 2020). Chronic pain acceptance was hypothesised as an antecedent to living well with chronic pain. This has been a finding in a previous living well with chronic pain study (Lennox Thompson et al., 2020). The CPAQ-2 has demonstrated comparable variance to the Chronic Pain Acceptance Questionnaire-20 (CPAQ-20) (Vowles et al., 2020). Previous studies have demonstrated the psychometric properties of the CPAQ-20 (McCracken et al., 2004). These findings were summarised and are presented in Table 4 in the Results section.

Interviews

Semi-structured interviews formed the primary data for this study. The semi-structured framework provides the opportunity to focus on predefined topics of discussion whilst allowing the interviewer to probe more deeply through dialogue (Brinkmann & Kvale, 2018). The semi-structured interviews aimed to explore participants' experiences from their perspective to understand how they view living well with CRPS.

Interviews were either completed online or face-to-face if COVID restrictions and geography allowed. Interviewees were advised to expect an interview between 30-90 minutes. To prompt a strength-based discussion, interviewees were provided with a list of topics for discussion before their interview. Open-ended questions were used to explore the personal experiences and sensemaking processes of living well with CRPS. I adopted an iterative process to the interview structure to ensure responsiveness to content. Each interview offered a point of reflection, updating future interviews following note-taking through my reflexivity journal. The list of question recommendations, prompts to engage dialogue, and topics of discussion are attached to the interview schedule in Appendix F.

Interviews were audio recorded through the primary researcher's phone recorder when face-to-face or through Zoom when online. All interviews were then transcribed from audio using a verbatim orthographic transcription into Microsoft Word, where the comment function was used for note-taking. All interview data (audio and text) were saved and password protected on AUT’s Sharepoint Online.

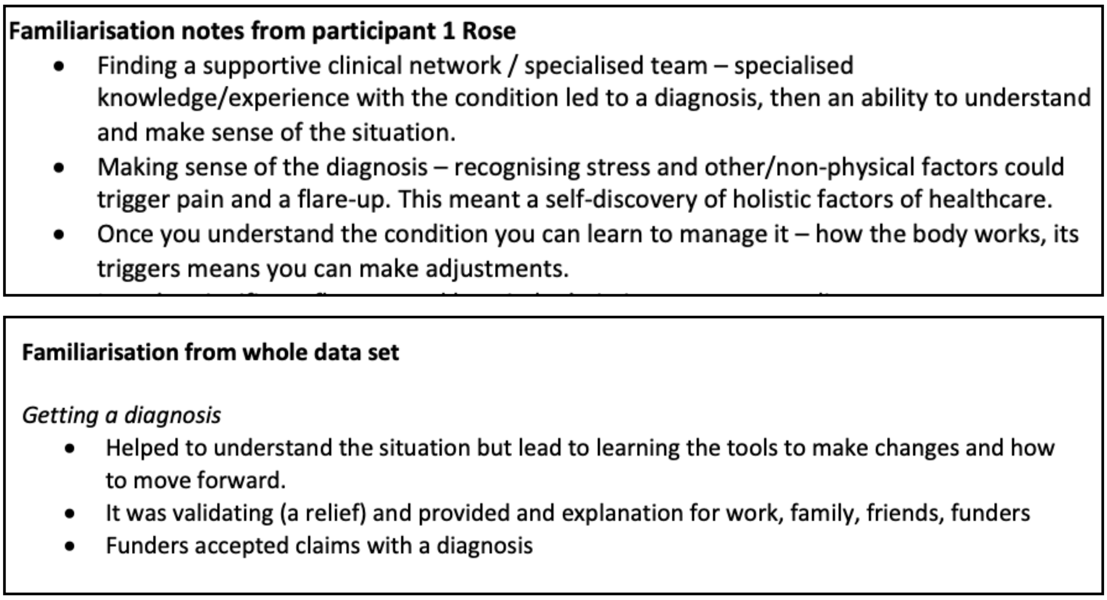
Data Analysis

Data analysis was conducted following the most recent articulation of Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2021b). Within reflexive thematic analysis, rigour is achieved through engagement with the data rather than reliability or trustworthiness frameworks (Braun & Clarke, 2021b; Terry & Hayfield, 2021). Therefore, I followed the analytical method framework developed by Braun and Clarke (2021b) closely to maintain methodological rigour throughout the study. This included the following phases: *familiarisation*, *coding*, *generating initial themes*, *developing and reviewing themes*, *defining and naming themes*, and *writing* (Braun & Clarke, 2021b). I have outlined my process for each phase below:

Familiarisation. As the interviewer, transcriber and primary researcher, my engagement with the data began during the recruitment stage. Through interviewing and transcribing, I was ensuring full immersion and engagement in the data. I read and re-read all transcripts, taking notes and writing reflections for each participant. My notes included personal reflections and curious thoughts as to how this participant was making sense of their experience of living with CRPS. An example of note-taking included: "*Once you understand the condition you can learn to manage it – how the body works, its triggers, means you can make adjustments."* An example of participant and whole data familiarisation notes are illustrated in Figure 4. After the 10th interview, I made collective notes summarising the whole dataset.

Figure 4

Example of Familiarisation Notes



Familiarisation notes from participant 1 Rose

- Finding a supportive clinical network / specialised team – specialised knowledge/experience with the condition led to a diagnosis, then an ability to understand and make sense of the situation.
- Making sense of the diagnosis – recognising stress and other/non-physical factors could trigger pain and a flare-up. This meant a self-discovery of holistic factors of healthcare.
- Once you understand the condition you can learn to manage it – how the body works, its triggers means you can make adjustments.

Familiarisation from whole data set

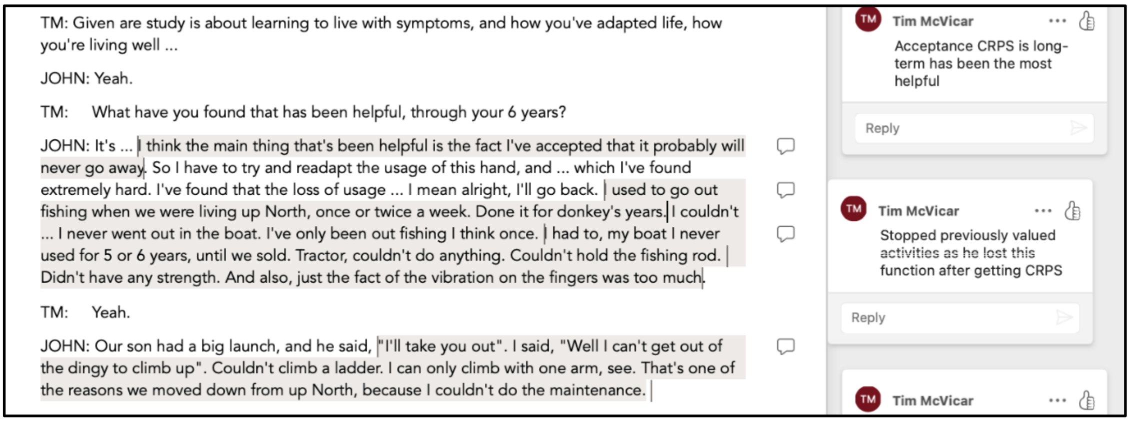
Getting a diagnosis

- Helped to understand the situation but lead to learning the tools to make changes and how to move forward.
- It was validating (a relief) and provided and explanation for work, family, friends, funders
- Funders accepted claims with a diagnosis

Coding. After the final transcription and familiarisation note-taking, I started the initial coding process. I coded using the comment function on Microsoft Word in an open-annotated style updated in a recursive manner. I aimed for open-ended and organic coding, using both semantic and latent codes in an inductive approach. Semantic refers to generally accepted meanings of words and phrases, while latent refers to implicit meanings (Braun & Clarke, 2021b; Terry & Hayfield, 2021). Latent coding allowed me to reflexively engage with the data, whereby I (the researcher) make sense of the interviewee's (the participant's) sensemaking approaches to living well with CRPS. To think critically and interrogate the data, I used the following set of prompts "What function does this behaviour serve?" "What are they trying to accomplish?" "How did they do this?" "What assumptions are they/I making?" "What do I see happening?" "Why do I think they believe this?" Although coding reliability and multiple coders are not a feature of reflexive thematic analysis, I thought it was important as a novice researcher to ensure my coding was sufficient to represent the dataset. I, therefore, asked my primary supervisor (DB) to code one participant so we could discuss the depth of my coding with an experienced researcher. An example of coding for the quote, “It’s one of things that it’s not easy to address the issues. Like absolutely every time I addressed them, I cried but in the long run it has been far more helpful than focussing on physical therapies”: *“Addressing stress was far better than any physical therapies.”* An example of coding is illustrated in Figure 5.

Figure 5

Example of Coding



TM: Given are study is about learning to live with symptoms, and how you've adapted life, how you're living well ...

JOHN: Yeah.

TM: What have you found that has been helpful, through your 6 years?

JOHN: It's ... I think the main thing that's been helpful is the fact I've accepted that it probably will never go away. So I have to try and readapt the usage of this hand, and ... which I've found extremely hard. I've found that the loss of usage ... I mean alright, I'll go back. I used to go out fishing when we were living up North, once or twice a week. Done it for donkey's years. I couldn't ... I never went out in the boat. I've only been out fishing I think once. I had to, my boat I never used for 5 or 6 years, until we sold. Tractor, couldn't do anything. Couldn't hold the fishing rod. Didn't have any strength. And also, just the fact of the vibration on the fingers was too much.

TM: Yeah.

JOHN: Our son had a big launch, and he said, "I'll take you out". I said, "Well I can't get out of the dingy to climb up". Couldn't climb a ladder. I can only climb with one arm, see. That's one of the reasons we moved down from up North, because I couldn't do the maintenance.

Tim McVicar
Acceptance CRPS is long-term has been the most helpful

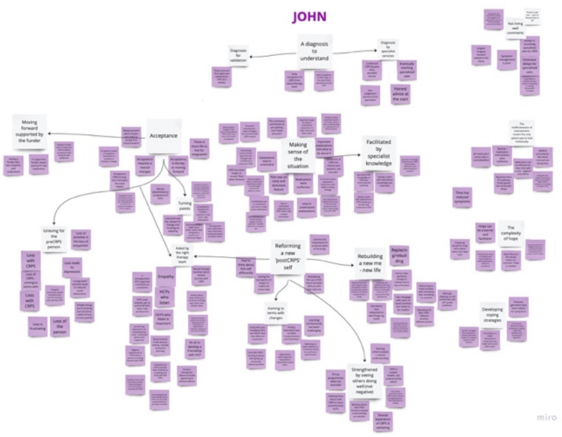
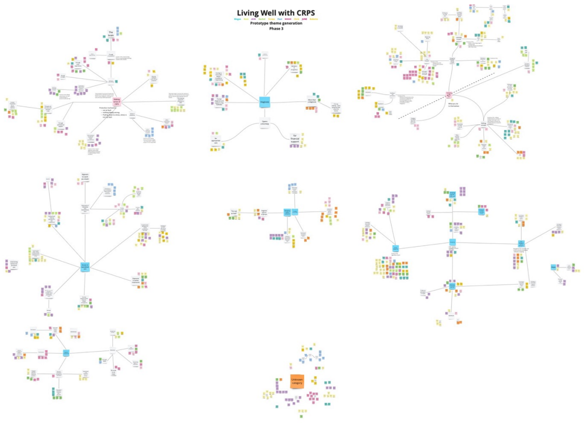
Tim McVicar
Stopped previously valued activities as he lost this function after getting CRPS

Tim McVicar

Initial Theme Generation. Once all transcripts were coded, I used a macro to download all open annotated comments from Microsoft Word onto Microsoft Excel. The Excel document included the highlighted portion of text from the transcript, the annotated code, and the participant's pseudonym. All 903 individual codes were imported into Miro, a digital collaboration platform (Miro visual workspace, 2023). This appeared as 903 individual ‘Post-it’ notes on the desktop. I then developed thematic maps on Miro, firstly by individual maps for each participant, then collating all maps to form an entire data set. Maps were re-organised by gathering similar and overlapping constructs and noting areas of contradiction. Prototype themes were then generated following a discussion between my primary supervisor (DB) and I using the Miro board. Convergent and divergent themes were then thoroughly discussed with a secondary supervisor (BLT) who is experienced in qualitative methodologies. The initial theme generation was broad and descriptive: “*Making sense of the presentation.”* An example of the initial participant thematic map and prototype theme thematic map is illustrated in Figure 6.

Figure 6

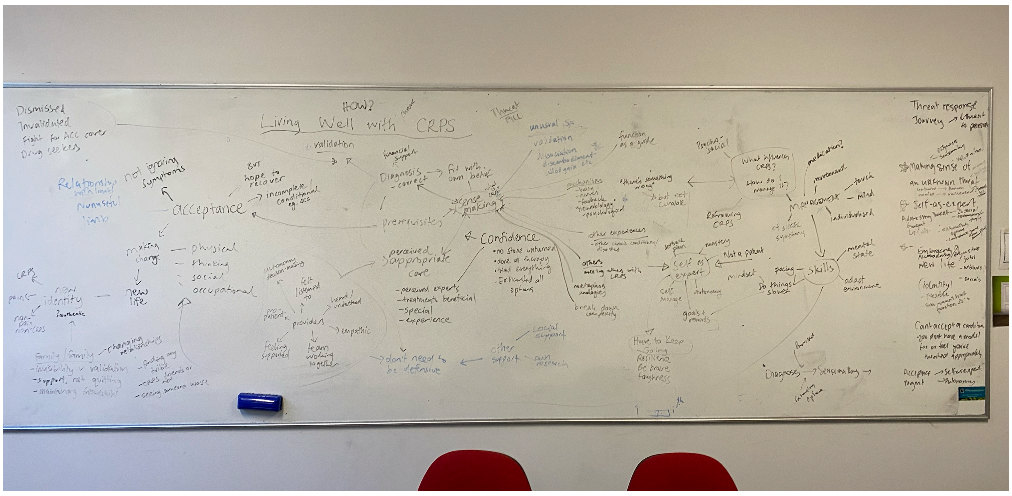
Example of Thematic Maps in Miro

Individual participant thematic map	All participants prototype themes
	

Developing and Reviewing Themes. Through a recursive and iterative process, I generated themes by deconstructing, rebuilding, and promoting prototype themes. This included collectively discussing overlapping themes and subthemes with both my supervisors. This process was also facilitated with face-to-face discussions using a whiteboard once the data was refined. A photograph of the white board theme development is attached in Figure 7. I also created an additional Excel document with the quotes of the themes to ensure there was sufficient data to support the theme. Additionally, I felt it was important to respect the CRPS community I was representing; therefore prototype themes were discussed for resonance with an expert patient acting in an advisory role for the duration of the study as discussed in the researcher positionality statement. Although ‘data saturation’ is not a congruent term in reflexive thematic analysis (Terry & Hayfield, 2021), I continued this process of developing and reviewing until my two supervisors and I felt the themes represented the dataset.

Figure 7

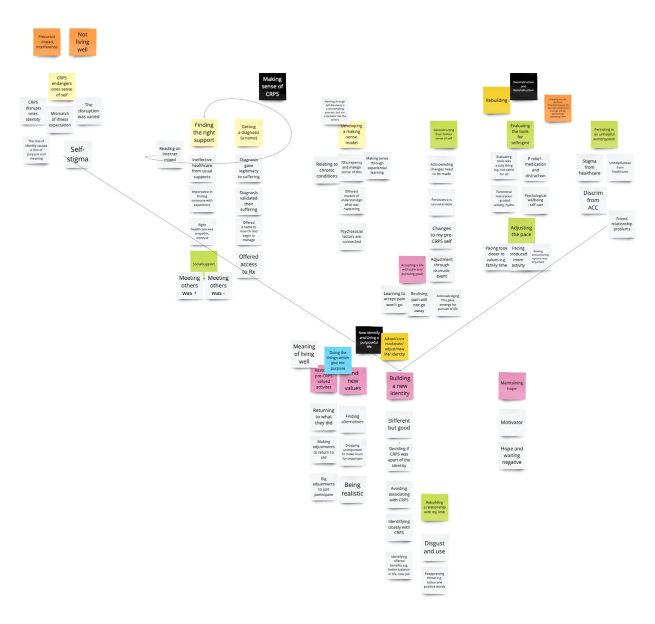
Whiteboard Session for Developing Themes



Defining and Naming Themes. I continued this process until refining the themes produced a clear distinction with no overlap between themes. I strived for rich and multifaceted themes characteristic of the participants' stories and my interpretation of their sensemaking. I discussed and collaborated with both supervisors until we felt the theme names and subtheme names appropriately represented the data, e.g. *"Making sense of my new life with CRPS."* Diagramming was later developed through collaborative discussion between the research team to support themes in a visual sense. A copy of the final thematic map is illustrated in Figure 8.

Figure 8

Final Theme Generation



Writing. Throughout the writing process, I was able to further articulate my reflections, adjusting the boundaries of themes and subthemes. Completing the literature review at the time of writing the analysis provided further reflexivity and sensemaking by contextualising themes in the wider sociocultural context of CRPS and chronic illness literature. I feel this made me question the experiences these participants were articulating more deeply. Braun and Clarke (2021b) consider the writing phase as an iterative process as themes are cross-referenced with supporting quotes to ensure they represent the context in which they were discussed. To maintain 'good practice' within reflexive thematic analysis, I followed the writing and reporting chapters of both Braun and Clarke (2021b) and Terry and Hayfield (2021) recent derivation of reflexive thematic analysis. This includes a researcher reflexivity statement, a detailed description of the procedure, participants, and data analysis.

Quality in Reflexive Thematic Analysis

Lincoln and Guba's evaluative criteria for qualitative research describe the trustworthiness of research as establishing credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Qualitative research employs many techniques for trustworthiness, such as saturation, multiple coders, and triangulation (Denzin & Lincoln, 2018). As discussed at the beginning of this chapter, Braun and Clarke (2021b) argue these techniques are features of 'small q' or positivist qualitative research. Such techniques make the assumption there is a 'single truth' to reality which contradict the philosophical paradigm, interpretivism underpinning this study. Reflexive thematic analysis is framed as a ‘Big Q’ approach (Kidder & Fine, 1987) embedded within qualitative philosophy (Braun & Clarke, 2021b). The next few paragraphs will detail how reflexive thematic analysis relates to traditional measures of trustworthiness.

Data saturation refers to information redundancy (Denzin & Lincoln, 2018). In qualitative research, thematic saturation is achieved largely through sample size and data collection (Morse, 2000). Within reflexive thematic analysis, sample sizes are determined based on the collection, quantity and diversity of data (Braun & Clarke, 2021b; Terry & Hayfield, 2021). In their 2019 research review named *“To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales,”* Braun and Clarke (2021c) did not advocate for predetermined sample sizes but instead using a pragmatic decision based on answering the research question. The term saturation has positivist orientations, assuming there is a single truth waiting to be discovered (Braun & Clarke, 2021c). As the term ‘saturation’ is not commonly accepted in reflexive thematic analysis and upholding the spirit of “Big Q” research, the sampling in this study adopted a pragmatic approach to my time as a part-time Masters researcher and aimed for ten interviews. Terry and Hayfield (2021) supported this, suggesting that 6 to 10 participants may be sufficient for data that is ‘thicker,’ where each participant makes a significant contribution. The research team continued data engagement and theme development until we felt there were no additional themes gained by further interviews.

Multiple coders aim to reduce the researcher bias, strengthening the confirmability of the research (Denzin & Lincoln, 2018). However, within reflexive thematic analysis, the value of researcher subjectivity is featured as an analytical resource (Braun & Clarke, 2021b). *Reflexive* references reflexive engagement with the data; thus, aiming for objectivity is incongruent with reflexive thematic analysis. The present study achieved quality through prolonged engagement with the data, adhering to phases 1 to 6 of the reflexive thematic analysis method (Braun & Clarke, 2021b). Additionally, the reflexivity interview and positionality statement also ensure the reader can add context to the findings.

Triangulation is considered a validation strategy by observing the research from at least two different points (Denzin & Lincoln, 2018). Criticisms of triangulation are the assumption of a single truth that can be observed in total by using a variety of research methods (Flick, 2018). One such example of triangulation enhancing trustworthiness may be through member checking (Denzin & Lincoln, 2018). However, several authors suggest this concept is a realist approach and, therefore, does not align with reflexive thematic analysis (Braun & Clarke, 2021b; Terry & Hayfield, 2021). Tracy

(2010) argues that *member reflections* make more sense for reflexive thematic analysis as we are not concerned with verifying what is true, instead it offers an option for dialogue, reflexivity and deeper engagement with the data. This study consulted someone living with CRPS to help confer resonance of themes and terminology to represent the CRPS community. This has been detailed in the positionality statement (see page 41).

The question then arises, *how do researchers maintain quality within reflexive thematic analysis?* In their 2021 paper, Braun and Clarke detailed a 20-point checklist for guiding the assessment of the thematic analysis research quality (Braun & Clarke, 2021a). The checklist ranges from 'choices and explanations of methods and methodology' to 'developing and justifying the analysis'. Notably, this includes "researchers to reflect on the relationship between analytic practices, including quality practices, and the ontological and epistemological foundations of their research, and to use TA knowingly, deliberatively and reflexively" (Braun & Clarke, 2021a, p. 346). Additionally, Terry and Hayfield (2021) advise quality in reflexive thematic analysis comes with prolonged engagement with the data and methodological justification rather than constraining frameworks. I therefore believe the preceding sections, including researcher positionality, interpretivist philosophical paradigms, reflexive thematic analysis, and methods, have demonstrated adequate methodological rigour. A copy of the 20-point checklist by Braun and Clarke (2021a) followed for this section is attached in Appendix E.

Chapter Three Summary

This chapter provided oversight of reflexive thematic analysis as a method within interpretive philosophical paradigms that underpin this qualitative inquiry. It illustrated that purposive sampling and recruitment strategies were used to interview a difficult-to-reach and underrepresented population in research. It demonstrated the methods employed to honour the voice of those living with the condition whilst maintaining quality to respect their experiences. The results of this analysis will be presented in Chapter Four: Findings. That chapter will detail how people living with CRPS describe living well despite their condition.

Chapter Four: Findings

Participant Characteristics

Thirteen people enrolled for the study through the website portal. The first ten to enrol were invited for an interview. Two participants enrolled through social media advertising (Twitter). Two participants were recruited by the research team after they were featured in lived experience stories in the New Zealand Pain Society (NZPS) quarterly publication. One participant contacted the NZPS directly to participate in CRPS research. One participant was recruited by a PhD student of the secondary supervisor (BLT). Four participants were recruited through the primary supervisor's (DB) CRPS research database. After starting the interview phase, one participant declined an interview stating they had recently suffered a flare-up of their CRPS and did not feel they met the criteria of 'living well.' The three additional remaining applications were then screened using the CPAQ-2, with the highest score invited as the final participant.

Ten participants (7 female, 3 male) were interviewed for between 29 and 83 minutes. Participants were all recruited from New Zealand, with two conducted in person and the remaining eight online by video conference. The mean age of participants was 52.5 years (range 23 – 82 years), the mean time of symptom onset was 6.5 years (range 23 months – 16 years), and the mean delay until receiving a diagnosis was 1.4 years (range 0 months – 11 years). CRPS diagnosis was identified as lower limb in five participants, upper limb in four participants and trunk in one participant. All ten participants were European (9 New Zealand European, 1 British), with five in part- or full-time employment, two studying, and three retired.

The BPI mean pain severity score was 3.48/10 (SD 2.11), and the mean pain interference score was 2.73/10 (SD 1.67). Higher BPI scores indicate more severe pain and interference with daily functions (Cleeland & Ryan, 1994). The CPAQ-2 mean activity engagement score was 4.5/6 (SD 0.53), and the mean pain willingness score was 4.1/6 (SD 1.45). Higher CPAQ-2 scores indicate higher levels of chronic pain acceptance (Vowles et al., 2020). The self-reported CSS was 5.8/8 (SD 1.32). The minimum cut-off score for inclusion was 3/8 to ensure that all participants continued to meet the Budapest Criteria for a diagnosis of CRPS (Harden et al., 2010a). The details of all ten participants are presented in Table 4. The names are pseudonyms chosen by each of participants.

Table 4

Participant Characteristics

Name	Gender	Age (Y)	Ethnicity	Relationship	Education	Work status	Time since symptoms (y/m)	Time since diagnosis (y/m)	Body part	BPI		CPAQ-2		CSS (/8)
										Pain intensity (/10)	Pain interference (/10)	Activity engagement (/6)	Pain willingness (/6)	
Rose	F	23	NZE	Prefer not to say	Bachelors	Studying	3y	2y 10m	Lower limb	0	0	5	1	3
Megan	F	54	NZE	Married or de facto	Bachelors	Part-time	16y	5y	Trunk	3.5	1.4	5	6	6
June	F	67	NZE	Married or de facto	Postgraduate	Full time	1y 11m	1y 2m	Upper limb	4	4.4	5	4	7
Roberta	F	24	British	Single	Bachelors	Studying	3y	1y 8m	Upper limb	8	4.8	4	3	8
Chris	M	44	NZE	Married or de facto	Postgraduate	Part-time	3y 4m	3y 4m	Lower limb	3.75	5	4	5	5
John	M	82	NZE	Married or de facto	Certificate	Retired	6y	6y	Upper limb	5.25	3.6	4	4	6
Maggie	F	64	NZE	Married or de facto	Highschool	Part-time	8y	8y	Upper limb	2.75	2	5	5	6
Teresa	F	67	NZE	Married or de facto	Certificate	Retired	10y	10y	Lower limb	1.75	1.29	5	5	5
Paul	M	65	NZE	Single	Less than Highschool	Retired	10y	10y	Lower limb	3	2.71	4	5	6
Rachel	F	51	NZE	Married or de facto	Bachelors	Part-time	4y 4m	4y 0m	Lower limb	2.75	2.14	4	3	6
									Mean:	3.48/10 (SD 2.11)	2.73/10 (SD 1.67)	4.5/6 (SD 0.53)	4.1/6 (SD 1.45)	5.8/8 (SD 1.32)

Note. M = Male, F = Female. Y = Years, y/m = years/months. NZE = New Zealand European. BPI = Brief Pain Inventory CPAQ = Chronic Pain Acceptance Questionnaire. CSS = CRPS Severity Score

All names are pseudonyms.

Living Well With CRPS Study Findings

The overarching theme identified in the narratives of the participants is that living well *with* CRPS was the product of a journey. While all ten participants in this study identified as living well *with* CRPS, they acknowledged this was not always the case. This introductory section will outline the journey from symptom emergence to the day of the interview. To understand the phenomenon of living well, I asked participants, “What is ‘living well’ with CRPS?” Participants started their narratives by describing how their experience at the time of being interviewed differed from earlier in their recovery, illustrating the contrast of ‘not living well.’ Listening to their stories, I termed this “living *against* CRPS.” Participants thought it was important to emphasise the journey from where they had come to where they are now. The initial section will describe the journey from living *against* CRPS to living well *with* CRPS to contextualise the narratives describing living well. The subsequent sections will explore the second question “What processes were necessary to get to a point of living well with CRPS?” Here, I discuss the three themes related to the journey towards living well. First, “Making sense of my new life with CRPS,” with subthemes titled “Making sense through a diagnosis,” “Making sense through information and support,” and “Making sense through an evolving conceptual model of CRPS”; second “Taking control in a seemingly uncontrollable world,” with subthemes “Taking control with the support of professionals,” “Taking control by evaluating tools for self-management,” and “Recalibrating a new pace of life”; and third “Rebuilding a purposeful life with a new identity,” with subthemes “Accepting my new life with CRPS,” “Rebuilding purpose and meaning,” and “Reconstructing a new post-CRPS identity.”

Living *Against* CRPS: The Disrupted Sense of Self

The first emergence of CRPS symptoms produced pain unlike any injury or surgery participants had experienced before: “I felt like I was burning from the outside… I can't even describe the pain, just the most hideousness, unescapable” (Chris). They struggled to make sense of the intense, confusing, and unexplainable symptoms:

> I was just a bit confused as to how I could be experiencing all this pain. Like I couldn’t walk, I couldn’t put pressure on my foot, but everyone kept asking me if I could. But there was nothing wrong with me, so it was kind of like, what… what is causing me to feel this way. (Rose)

To make matters worse, healthcare was commonly ineffective with many participants describing disappointing outcomes, failed treatments, and no further explanation for their newfound incapacity: “He tried a full range [of medications]. But nothing worked. Nothing worked at all…. I’ve tried so many medications. If anything, they actually made my symptoms worse” (Roberta). When the medical system could not account for their suffering, participants often reported being subjected to stigma and blamed: “They rolled their eyes” (Maggie); “I don’t feel I’m a malingerer” (June); “trying to attention seek…. trying to go pill-popping” (Rose); “I was more a curiosity than a person” (Chris); “They start asking you whether you think you’re depressed" (Megan); “I was always being brushed off or put to the side” (Roberta). Participants often reported a time when they questioned the legitimacy of their own experience, searching for an explanation for their presentation. Not uncommonly, participants described self-stigma hoping to make sense of why they developed symptoms:

> Because it then just was in my face all the time and I couldn’t shake it off. And [I] was going, how the hell am I going to get rid of this? Is there something wrong with me? Is it my fault? Did I, what did I do to bring this on? Should I have not done something? Is it hereditary? (Paul)

Many reflected on the additional burden stigma placed on their already overloaded capacity to cope. Thus, the initial stages of living *against* CRPS were characterised by symptom dominance, loss of physical function and independence, compounded by numerous disappointing healthcare endeavours, and experiences of blame and stigma.

Participants initially coped by living ‘in spite of’ their symptoms. Living *against* CRPS meant sometimes disregarding the reality of their condition hoping their symptoms would resolve: “I was just trying to hide it and ignore it and see if it would go away” (Rose); “I wasn’t prepared to not, never work, never walk on uneven ground again or never work as a nurse again” (Rachel); “In the early days it was pushing too hard, too fast and trying, you know like, you’re going to do this, you’re going to get over it” (Teresa). Resisting acknowledging the severity and longevity of CRPS likely functioned by allowing participants to retain their previous sense of self. However, when their symptoms failed to resolve, participants reflected that continuing to live their lives ‘in spite of’ their condition only contributed to a self-perpetuating cycle of pain and disability:

> From going from a teacher, with 200 kids a day, colleagues that you talked to all day, and events, to all of a sudden sitting at home, frying in a little corner. (Chris)

> So you know the longer you go, the more likely you are to do less. So you end up with this life that is smaller and you feel crap about that. So, on top of feeling crap because you’re feeling so terrible, you feel crap because you are socially isolated and things, yea. (Megan)

The vicious cycle of pain and loss of independence had a more profound impact than just the withdrawal of social and vocational roles. The withdrawal of activities that defined their pre-CRPS self-concept led to the disruption of their wider state of being:

> I think that everyone searches for some sort of purpose and passion, and for a long, long time, I’d had this job that I absolutely loved. That people absolutely loved me when I was

> doing it. So, not only did I lose that, I also lost the psychological income that came with that. So, I felt quite worthless. I felt like I wasn't pulling my weight in our relationship. (Megan)
>
> I've fished all my life, and then suddenly to not have it, it was real... And also, the fact that, alright, I can't work on the cars, I can't do as much. I used to do a lot of woodwork and make things and everything like that. I had a big workshop. And, I mean, I couldn't do that. And that is a sort of big loss, that part is. (John)

While initially characterised by symptom dominance and their strive for resolution, living *against* CRPS eventually developed into the loss of activities of meaning and purpose. Because these activities were often fundamental aspects of participants' identities, living *against* CRPS resulted in the disruption of their sense of self.

The Perspective Shift

The transition to living well *with* CRPS required a shift in perspective from living 'in spite of' to 'living with' their condition. Often, there was a lightbulb moment instigating the shift from passive recipients of healthcare to actively involved in their recovery:

> So, I was like, if anyone's going to help me, it's me. I'm the only one who can dig myself out of my hole. It's not what I caused for myself, but it doesn't matter how it occurred or anything like that. I just had to have that moment where I was just frustrated beyond belief and just went, "I'm not going to... this isn't going to be my life." You know? I'm not going to allow this to be me. (Chris)

For the participants in our study, many started to recognise that their way of coping ironically moved further away from the lives they wanted to live. Identifying that living *against* CRPS was not permitting them to live meaningful lives alongside their condition formed the defining moment in the shift from living *against* to living well *with* CRPS:

> First up, I had to decide to get myself out of the way. Because I thought I knew better, and continuing to think that way was not going to allow for any change, and so, you know, if you continue to do the same thing, you're going to get the same result. (Megan)

A defining feature of living well *with* CRPS was the recognition that living *against* CRPS disrupts one's sense of self, and to restore that sense, something needed to change.

The time spent living *against* and the transition to living well *with* CRPS varied. For some, the perspective shift was immediate, catalysed by a dramatic event. Rose described an Accident and Emergency Department (A&E) admission as the catalyst she needed to change her way of coping:

> I was in A&E, and that was probably the most uncomfortable I had ever been, and I guess for me, I really don't want to be back here. So, I was going to do all that I can to make sure I don't end up in this situation again.

For John, a moment of clarity and self-realisation emerged during a time of acute distress and near self-amputation:

> I reached a part of my life where I was so depressed that I actually went down into my workshop. I got a small axe, put my finger down, and I was just going to chop it off because I couldn't get the hospital to remove it. Then I stopped, and I thought, "What the hell are you doing?" And I think that was the turning point of where I accepted that I had this, and I had to get out of this depressive, depressed state and think, well, there is, you know, still life around.

Participants reflected on these profound moments as a watershed in their journey to living well *with* CRPS. For a few other participants, the transition to living well was more acceptable due to previous experiences of self-managing other chronic conditions:

> People with asthma have to live with it. People with diabetes have to live with it. My husband has got a pacemaker, and he has to take lots of medication, and he's got a strict diet and exercise regime, and he's got to live with that. So that's what you got to do. (Maggie)

People living with or knowing others with chronic conditions normalised the idea of living well through self-management. In summary, there was no single right way or timeframe for those shifting perspectives. The one consistency was that there was always a process.

Living Well *With* CRPS: The Restored Sense of Self

The common narrative that connected the accounts of those living well *with* CRPS was the moves toward restoring a sense of self alongside their painful limb. Living well was a subjective phenomenon, individualised to each participant within our study, yet restoring purpose and meaning in a new life and identity was evident in all conversations. The notion of restoring a sense of self was the deeper exploration of their foundational values:

> So, for me, [living well] looks like being someone who can participate well with my life. By that, I mean I have a social life, I have a sporting life, I have a love life, I have a family life, I have hobbies, you know. (Megan)

Living well *with* CRPS was the emphasis that life, relationships and social identities were not defined by their CRPS:

> Being able to do, yea simple things, like being able to go to a restaurant with friend or being able to drive to a friend's house to have dinner with them. That freedom part is really, really valuable and as long as I can take care of myself, again in that holistic way, I can know that I can achieve that freedom and that it's completely possible. (Rose)
>
> Going forward I'm going to be a grandmother shortly and then I'm going to help care for my granddaughter when my daughter goes back to work. So, you know, if I'm not well enough that means that I couldn't then look after her and then that would affect my daughter's ability to work, then you know. So actually, that's why I say I have to make sure I exercise every day and I eat properly every day and I, so I have these things that I do, yeah. (Megan)

Rather than view themselves as broken, battling by living *against* CRPS, participants became more accepting of their symptoms:

> It's okay to be in pain. There's no shame in it. A lot of people just think it's like, 'how dare you be in pain.' Like, who cares, man? Like, if you're in pain, you're in pain. Like, can't do anything about it. Like, it's just one of those things who've got to accept. (Roberta)

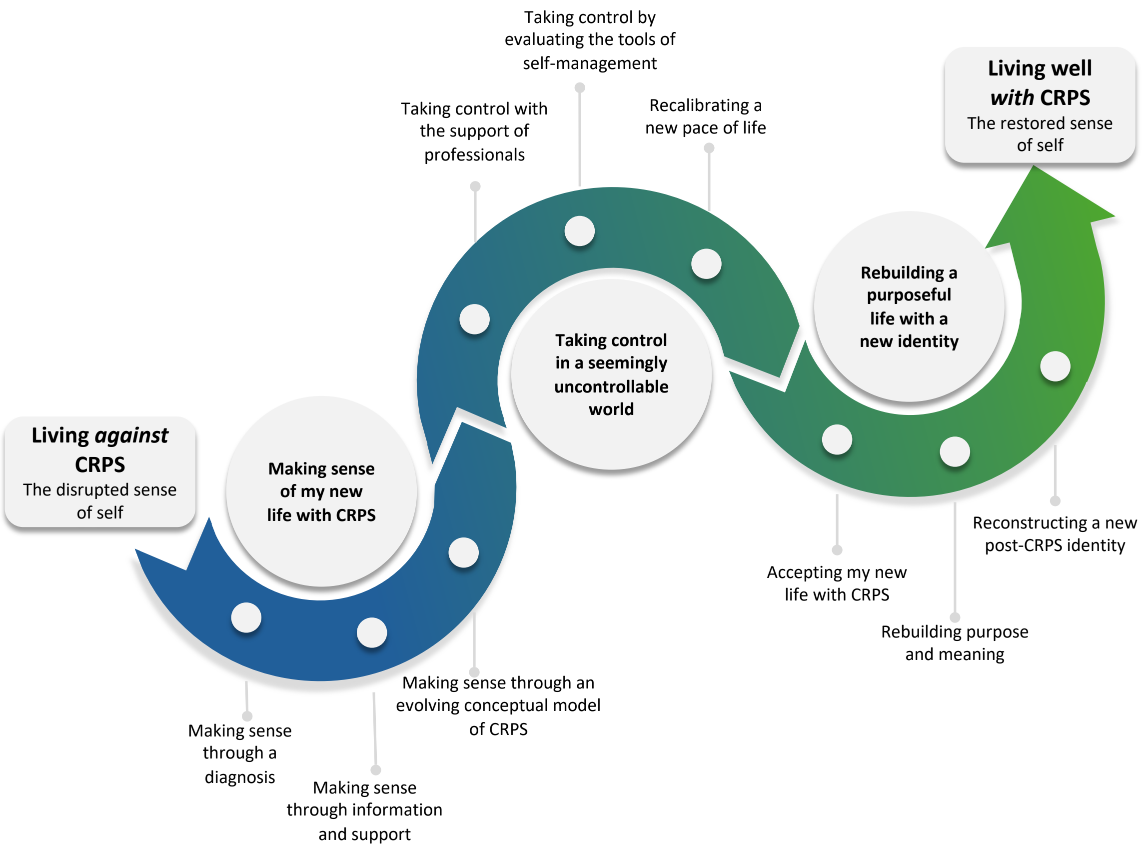
Like restoring a piece of furniture, restoring a new sense of self was not a matter of replacing and rebuilding, but rather acknowledging their scars and struggles of living *against* CRPS whilst working toward their new life *with* CRPS. Participants did this by expressing their foundational values in a new life of purpose and meaning.

In summary, living *against* CRPS was perceived as a daily struggle characterised by symptom dominance, navigating an unhelpful medical system and searching for a cause or reason for their incapacity. CRPS dominated their energy forcing the withdrawal of fundamental features of their identity. Conversely, living well *with* CRPS was characterised by the restoration of their sense of self by the rebuilding of purpose and meaning in their lives. Note, the use of '*with'* (italicised) is to emphasise the importance that living well *with* CRPS was the focus on living alongside, in partnership with, their painful limb. Importantly, their symptoms did not disappear and may not ever, yet the overall impact of CRPS has reduced.

The following three themes encompass the journey participants took to restore their sense of self and reach the point where they considered themselves to be living well *with* CRPS. I will aim to articulate their perspectives on navigating this journey whilst embedding their descriptions with critical analysis of the factors these participants had to enable this process. Participant quotes will be introduced with a short description of the participant. Each theme will be bookended with a starting quote emphasising the 'living *against'* period with a partnered quote on completion summarising the 'living well *with* CRPS' period. The summary of all participant quotes is featured in Table 5 (see page 88). An illustration of their journey is featured in Figure 9 (see page 66) supplemented by a pictorial representation of the journey to living well with CRPS in Figure 10 (see page 87).

Figure 9

The Journey of Living Well With CRPS: Themes and Sub-themes



Theme One: Making Sense of My New Life With CRPS

> *I mean, I need to know something is happening in my body. I need to know why. Otherwise, it gives you… it worries you. You think, what is happening? (Teresa)*

A characteristic of those living well *with* CRPS was the desire to become informed. Participants searched for a deeper understanding by getting a diagnosis, researching, and talking with their peers and family members. They used this information gathering as a means to make sense of their condition and its impact on their lives. They developed a conceptual model of CRPS through testing, reappraising experientially, and updating their model iteratively through time. The desire to make sense of their symptoms and the impact CRPS had on their lives was the first step towards living well *with* CRPS.

Making Sense Through a Diagnosis

Obtaining a diagnosis served an important, yet different function, for each participant. At its primary level, a diagnosis provided a rationalisation to make sense of the symptoms they were experiencing. June, a psychologist with upper limb CRPS, summarised getting a diagnosis as the starting point for sensemaking:

> I didn't know about CRPS, to be honest, and I think it's quite a secret squirrel society almost. So, actually having a label enabled me to do some looking, and thinking, and reading, and researching, and getting information about pain and management. (June)

A diagnosis acted as an articulation of the unknown. Participants now had a name for which they could account for their suffering. At a deeper level, giving their symptoms a name provided participants with a sense of reassurance, validating their experience and affirming the legitimacy of their symptoms: "Because I thought, 'Well, I'm not going completely mad here'" (June). For Roberta, a student with upper limb CRPS, a diagnosis eased anxieties of the unknown: "For me, that just lifted a weight off my shoulders." She further described the function of a diagnosis in reassuring yet validating terms:

> Mainly just like knowing I wasn't going insane. Like, I was saying, like, I was in so much pain, and people were like, "You're just being a drama queen, it's in your head." And to know it's not in my head. So just like getting that diagnosis was like hallelujah.

For others, a diagnosis offered practicalities in communicating their situation. Megan, an interior designer with CRPS of the trunk, described a diagnosis as a "shorthand… that you can say something to explain," adding, "I don't look sick, so it was sometimes easy to have an explanation that you can say to other people." This tangible label gave participants the words to communicate their suffering easily, partially countering the invisibility of chronic pain.

However, in some instances, a diagnosis unexpectedly contributed to further challenges. Rachel, a nurse with lower limb CRPS, described self-stigma associated with her preconceived perceptions of CRPS:

> Only because I'm a nurse because then it's been, you know, especially in the surgical environment if you know, well, in the past, if you thought you were getting a patient with chronic pain that they would be a bit nuts or there would be something a bit mentally wrong with them, or they would be a bit soft. You know, there was a lot of negative connotations to being a chronic regional pain person, really [sic]. So no, it wasn't helpful.

For Megan, a diagnosis itself was described as "meaningless." Her primary goal for making sense was to inform treatment and better manage her life with chronic pain: "Like I actually wanted to know what I could do, more than anything else. Was there anything that would improve my quality of life?" In her case, a diagnosis was viewed as a practicality to inform treatment in the journey towards living well. Overall, receiving a diagnosis of CRPS contributed to a sensemaking process by validating and explaining the symptoms, providing a means to communicate to others, and mechanisms to secure and source treatments.

Making Sense Through Information and Support

Accessing trustworthy information to understand how to manage their condition was challenging for participants. June described feeling lost post-diagnosis due to the lack of information on how she should be managing her symptoms:

> No one gave me a sort of beginners' guide like that. You know, if you've got it, these are some good things to think about: how you tell your family about it, how you understand it, what else you can do, think about things other than just your arm.

Most participants used the internet as an initial step to make sense of their symptoms. Many had stories, both positive and negative, about their self-directed research online. Most agreed that the information available was unhelpful and surprisingly amplified their anxiety. Rose, a student with lower limb CRPS, described the threatening information she found online, "You'll never recover. You're going to have this forever. It sucks." Whilst Rachel recalled reading about her CRPS spreading, "Oh my god, it can move! It can go into your back and here, there, and everywhere." Several of the participants said healthcare professionals advised them to avoid researching on the internet: "The physiotherapist at the time said that 'I'm going give you information about it. Don't go on the internet and google anything. Just read what I give you.' For good reason" (Rose). The extent of the negativity online was evident for Chris, a teacher with lower limb CRPS, who decided it was better to avoid researching altogether:

> Because there is too much negativity, you know? You read the first thing, it's suicide, and then it's this, that, and the next thing, and all this other shit. And to be honest, a couple of times, I've been mega depressed. I'll be honest, like, pretty dark, in dark places, because you're just like, I can't get out of this embattlement. But it's just slowly unpicking it.

Despite the prevalence of unhelpful information online, a few participants found the internet offered an easily accessible means to understand their situation better. Roberta found that accessing Google Scholar provided her with a trusted resource to make sense:

> I went on Scholar, and just did Google, and a lot of stuff came up. And even like, pain management services like that helped too, education-wise.

Roberta was completing her second university degree and was experienced in appraising information for quality purposes. Those with less experience appraising literature quality found the available information untrustworthy, often leaving them with more fear and uncertainty. This prompted participants to look for alternate ways to make sense of their condition.

Meeting others with CRPS or attending CRPS groups allowed participants to make sense of their future through listening to the narratives of others. Participants also found those with a similar experience shared their resources and success stories:

> Yeah, and that's where the talking to each other has been really helpful and sort of been like, "I had this condition, I did this thing, I tried this, and it was really helpful." (Rose)

In addition to sharing resources, meeting others with lived experiences gave a feeling of mutual understanding, which could not be achieved with people who do not live with the condition. John, a retiree with upper limb CRPS, described this mutual understanding when saying, "[CRPS] is not something people can see. It is not something people, unless they've experienced it, actually can accept what it's like." For Paul, a retiree with lower limb CRPS, meeting others in a similar situation gave a sense of support: "It's good to be able to identify with somebody else. Then you don't feel so alone in the process." Finding a community of like-minded individuals offered a resource for support but also therapy in its own right:

> I think it is that ability to quickly form a rapport and have that, to make connect quickly so that those people feel heard and seen and, so importantly, not alone. Often, you'll find that people sort of relax at that point; it's like they've found their tribe. These people that they don't have to explain what living with pain is like. There is something wonderful about that. (Megan)

However, not all participants saw value in meeting others with CRPS. Several participants spoke of negative experiences of meeting others that were counterproductive to their journey. Chris recalled some interactions through hydrotherapy, "I met a few people with CRPS. And that wasn't a great experience, I'll be honest." He described the lack of positivity, which was difficult during the early stages of his journey: "They were real negative, you know, real like life had been tough on them with it." Teresa, a pharmacist with lower limb CRPS, believes the comparisons that occur within groups can trigger unhelpful thinking about one's own recovery: "I think everybody is different. Like the severity of people's can be very, very crippling, and you know, I think I'm not going there. I'm going to battle this and get over this myself." Less commonly, the act of meeting others provided perspective-taking rather than a shared understanding. Rachel found meeting others with more severe symptoms made her grateful for her level of function: "I think seeing other people worse off than me maybe makes you come to terms with how lucky I am." Due to the rare incidence of CRPS, meeting others offered several positive functions ranging from practicalities such as resource sharing to finding a community of people with a shared understanding. Many felt this information was less impactful when provided by people who do not live with the condition. However, the willingness to meet others appeared to depend on whether this offered positive functions rather than the experience of negativity and defeat.

Navigating changes to their social and intimate relationships was necessary to make sense of their future with CRPS. Communicating how CRPS influenced their intimate or sexual roles gave partners an understanding of the effect of allodynia, or painful touch, on intimate interactions:

> My husband is a really good support. So like, if it's really bad, I just say, "No, don't touch me," because you know, that's really, it's creepy, like it's so sensitive, and it creeps you out like. I don't know how to explain it. (Teresa)

Communicating one's needs openly gave loved ones a baseline understanding of their experience living with CRPS. Participants acknowledged that pain was an internal experience, often not outwardly visible. With communication, partners could accordingly adjust expectations and demands based on the day-to-day experience:

> I mean, pain is so nebulous. You know, people just don't know what that looks like. And actually, just trusting when someone is saying to you, "This is really painful for me." So, I think actually sharing that information, which I did, and I think that really, really helped my partner understand. (June)

Additionally, communication strategies were important for maintaining both friend and colleague relationships. However, openness and disclosure were less common, with participants stressing the importance of moderating their negativity in communication:

> And my mates have been really cool and rallied around me over time because I help myself as well, you know? And so, yeah, I haven't lost any of my mates because of it. But I realised really early if you go down the negative path, if I'd just been negative, that would have been it. My mates would have gone. (Chris)

It was common for participants to speak of friends and family lacking empathy. Unfortunately for Roberta, the relationships were not modifiable, requiring her to avoid disclosure and internalise her struggles:

> I think the main thing that would help people is like, really having that support at home. I never got that, and even now, I don't get that. So as soon as I'm home, I don't talk about my CRPS. It's non-existent; even though you can see that it's CRPS, but they don't know. (Roberta)

Broadly speaking, participants found that disclosure was important because it enabled friends and family to understand their condition and be willing to support their changes. For each participant, it was important to assess whether familial or friend support would change; otherwise, the internalisation of change was necessary.

Making Sense Through an Evolving Conceptual Model of CRPS

Using their understanding of the diagnosis, through information online or that provided by peers and healthcare professionals, participants developed a conceptual model of CRPS. Making sense through a conceptual model allowed them to manage their condition better and begin the journey toward living well *with* CRPS. Most of the participants adopted a neurobiological sensemaking model to understand their symptoms:

> It's pretty much like your central nervous system, just like becoming hypersensitive and, like, exaggerating your senses. (Roberta)

These neurobiological explanations for pain commonly relate symptoms to nerve sensitivity rather than tissue damage. Neurobiological sensemaking can add legitimacy, or a realness, to explain previously unexplained symptoms. For others, the specifics of neurobiology were less critical, instead making sense through broader non-specific terms:

> I think it's very much that your brain's being very kind to you, and it slams on the protective nature but hasn't taken the levers off. And so it's really saying, just be really, really careful. (June)

Viewing pain as an overprotective response served to reduce pain-related fear. Megan described the benefits of overprotective models as “you’re not damaging yourself further. Like we think it’s telling us to stop and so to know that it’s not telling you to stop.” The specifics of neurobiological or overprotective models differ, but the underpinning message remains the same: Individuals are safe to move.

For participants who identified a relationship between psychological distress and symptom exacerbation, they incorporated their known trigger into their sensemaking model. Both Rose and Chris linked stress with their symptoms, in a way they had not considered before developing CRPS:

> Whenever I had any exceptionally stressful situations, I’d experience a flare and then it continually got worse, and worse, and worse (Rose).
>
> If I get stressed for a day, day and a half, all of a sudden, I'll have four or five days of real challenging, unescapable burning. (Chris)

Those participants who feature non-physical factors in a more holistic view were either psychologically aware or had worked with biopsychosocial-orientated therapists. Rose reflected on her own learning process to view CRPS from a holistic lens:

> That was the real key. The key milestone in understanding that my health, for me, it’s very holistic. So, the way that I’m like, there’s the whole thing about fight and flight and being permanently in that elevated state due to stress, and if I’m in that state for long enough, changes are going to manifest in my body and in my physiology. Which is probably, partially, why my CRPS has developed over the last few years. So, sort of understanding that for me, everything is, it’s very connected.

Rather than remaining concerned with the stigma associated with psychological factors, Rose and Chris saw this as a strength to offer more comprehensive and holistic options to manage their situation.

The process of sensemaking was iterative and ever-evolving. Participants developed a model or hypothesis based on their prior understanding of pain, modified by the information provided following a diagnosis. These models were commonly tested, reappraised and continually updated using experiences from pain flares and treatment responses. Where appraisal outcomes exceeded expectations, a new updated sensemaking model was developed. Each model was more coherent and individualised, supporting them in moving closer to making sense of their new life with CRPS. Rose described her experiential sensemaking whilst hiking:

> So, for example, there was one trip that I went on at the start of the year. Where I'd start hiking in the morning, and I would end up having a flare, and I'd sort of go, "Oh, I'm not sure about this," but then I'd go, "I know I can. I did this for the last few days. I'm just going to be really gently walking. If it really doesn't get better, I know I can turn around, but I want to see if this will actually work." So, if I had not necessarily pushed through, because it wasn't that uncomfortable, but if I kept going and I was a bit more, like I wasn't absolutely racing through this hike, if I sort of was bit more gentle, a bit more, taking in the scenery, you know tiki tour style, it would actually end up fading and going away and I'd be ok to keep going and carrying on. But if [I] hadn't realised that about it, every time I had a flare, I would have gone, like, back to base and been like, "Hey look, I've got to come back. I can't do it today or whatever." So I guess, yea, the understanding of how my body works was really important.

In other cases, a conceptual model did not align with participants' experience, thus creating tension or a lack of coherence in their understanding. Commonly, participants spoke of a lack of coherence when healthcare professionals provided explanations that either did not make sense to their situation or did not match their pre-existing perceptions of illness. John reflected on a session with a psychologist where the education provided lacked coherence with his current sensemaking:

> She said, "What you've got to do, you've got to reprogramme your brain to accept it's all like this." And I said in the end, I said, "Look, I believe what you're saying, but, I said, you don't have any experience in this situation." I said, "What are you talking about, if you could listen to yourself, you were saying that if I programmed my brain, my fingers are going to grow again. Everything's going to be lovely." I said, "That can never happen." I said, "So I've got to accept it, and I can't accept it when you're saying it's my fault because my brain is not thinking the correct way.

In such cases, incongruent information was rejected in favour of a model which 'made sense'. Within the cohort, there was no consistency in how participants understood CRPS and its impact. Some chose to view CRPS from a neurobiological lens, whilst others rationalised more abstract means to understand the impact on their lives. Importantly, for a conceptual model to be retained, coherence had to be obtained from both an individual perception of illness and from experiential hypothesis testing. Regardless of the specifics, developing a conceptual model was an iterative process of sensemaking for participants, serving to rationalise their symptoms and the impact this had on their lives.

Making Sense of My New Life With CRPS Summary

I know my condition backwards now. I know what most of my triggers are, and it's just refining those things that make it better. (Chris)

For the participants in this study, sensemaking was the search for an understanding facilitated by a diagnosis and the subsequent steps to gain information. Within the cohort, people living well *with* CRPS expressed a desire to make sense of their situation, conveying not only a willingness but a readiness to comprehend. The desire and readiness to comprehend precede the perspective shift from living *against* to living well. Therefore, making sense of CRPS and its impact on their lives was the initial step in the journey toward living well *with* CRPS. Sensemaking was an active and ever-evolving process, updated and tested, reappraised for coherence. In this study, participants who formed a coherent model of their CRPS did so by reflecting deeply on self, symptoms, information and diagnosis. There was no consistency between models of sensemaking; rather, if the model was perceived to add value to understanding and move people towards living well, it was likely to be maintained.

Theme Two: Taking Control in a Seemingly Uncontrollable World

I was living every day by how my CRPS wanted me to live, because you have days when you can do some things, and then the next day you can't cope. (Roberta)

The second feature of living well *with* CRPS was the need to take control. In the 'Living *against* CRPS' introduction, participants described a lack of control, living life dictated by their symptoms. Roberta's opening quote to theme 2 epitomises the control CRPS commanded on the lives of sufferers. In the journey towards living well, participants wanted to take control of their condition to start the process of rebuilding their lives. As described in the *'The perspective shift'* section, participants determined that they needed to shift from passive recipients of healthcare to active self-managers. This process of self-management included navigating the landscape of healthcare professionals and trialling a range of skills and strategies to move towards rebuilding a new life.

Taking Control With the Support of Professionals

Initially, many participants leaned on the support of healthcare professionals to help guide them through the best ways to manage their condition. Participants emphasised the importance in finding the right type of healthcare professional. Primarily, the right type of professional was someone with perceived experience managing CRPS. Chris attributed his early successes to seeing a physiotherapist with CRPS experience: “My biggest moves forward were people who dealt with people who'd had CRPS.” Similarly, John described the confidence his musculoskeletal physician gave him by doing everything possible to improve his situation:

> He had done studies on CRPS. He'd been to America and done it, so he was knowledgeable about it. He knew about it. He didn't physically know with CRPS how it affected people, but he had done all the studies and everything else like that. (John)

Additionally, participants valued those who were perceived as pushing the boundaries, emphasising the importance of leaving ‘no stone unturned’: “They virtually tried everything, and that's what he said. Even though he said he was pushing the boundaries with ACC to give me drugs which weren't fully covered” (John). To focus on living well *with* CRPS rather than curing CRPS, participants needed to feel reassured there was no avenue left unexplored. Any perception of options left unexplored tended to shift their journey toward living *against* rather than moving toward living well *with* CRPS.

The ‘right’ type of professional also made participants feel listened to and understood. These person-centred skills were not typical of all healthcare professionals; therefore, participants valued these characteristics in their clinician:

> I guess for me, good support was just sort of listening if [I] needed to vent. Because sometimes I would just get super frustrated and be like, “I’ve had enough of this.” I need to just verbally vent to someone, people who would listen. They would listen, they would understand, and they wouldn’t necessarily hand out advice, like things like, “Have you tried Panadol? Have you tried Ibuprofen?” and I’m like, yeah, yeah, I have. (Rose)

The strong relationship built by their healthcare professionals gave participants the confidence that, above all else, they were doing what was best for them. Notably, a strong relationship went further than listening, preferably including a more resounding demonstration of empathy:

> I appreciated they saw me as a person. They knew what CRPS was, and they were understanding of that. More than understanding, they really got it, and they could talk to it, you know, and look at the weird and wonderful things my hand was doing and accept it. (June)

> There was one [healthcare professional] that I’ve had that I went to, and he, he said himself, “I have the feeling that for you, stopping you from doing things you enjoy is going to be worse for you in the long run than letting you do them,” and I was like, “You’re the first person, the first healthcare professional who has said that to me,” and I really appreciated him understanding that as well. (Rose)

Through effective listening, individuals felt they were being understood, giving them confidence that these professionals were exhausting all options to manage their situation. Therefore, taking control with the support of professionals meant working with healthcare professionals who were not only experienced but who prioritised developing a therapeutic relationship.

Taking Control by Evaluating Tools for Self-Management

Participants explored and trialled a range of tools to help them take control of their situation. Tools encompassed a range of self-management strategies learnt through self-discovery or provided by healthcare professionals and trusted peers. Initially, all participants searched for symptom relief or respite. Chris described his “biggest thing” became getting a “release from those symptoms.” He depicted the enduring nature of a person with CRPS as “they kind of get embattled, and then just constant, and all they can think of is their pain.” Commonly, medication was the first significant step toward taking control of their symptoms. Rachel recalled the initial days after trialling a tricyclic antidepressant, “suddenly I was able to actually walk a wee bit. I could do my normal things and not be too terrible and so, that was really amazing.” Medication was perceived as immensely beneficial if it took them closer to activities that gave them purpose and meaning. Rose portrayed the positive effects medication had on returning to tramping:

> Like this summer, I got to do a lot of tramping which I really, really enjoyed. Sure, I was taking quite a lot of medication at that point, but because I was taking that, it meant I could manage my symptoms and go out and do the stuff I really enjoy.

However, the effect of medication was not unanimously positive. For Roberta, medications offered no value: “I've tried so many medications, from tramadol, amitriptyline, and they didn't help. If anything they actually made my symptoms worse.” Similarly for June, the perceivable benefit of symptom relief was outweighed by the significant cognitive side effects of neuromodulatory medications: “I completely lost my brain and executive function for three months.” The mixed response to medication highlights the individual nature of pharmacological therapies, emphasising the importance for participants to explore non-pharmacological tools in conjunction with medication.

Distraction offered a medication alternative for reducing the attentional focus of pain. Participants found that cognitive engagement, through distraction, offered some respite from the constancy of symptoms. Chris described distraction as “finding anything that can distract you for as long as possible. Because afterwards, you go, ‘Hey, that was good, didn't even think about it.’” He recalled discovering that reading offered task-related analgesia, albeit temporarily, allowing him to sleep:

> I don't read a lot, 3 or 4 pages. And I found this steady bedtime. All of a sudden, I was getting a release from the CRPS, and I'd wake up at 5 in the morning, and I was like, feel like bloody Christmas. And so, I go to bed by 10.30 and I read my book. I have a release where actually I feel... It wakes me up every time that I feel completely normal. And I'm like, holy mackerel, this is what it's like to be... And I milk it. I just lie there and go, shit. I have no pain; I'm not burning. This is just bloody awesome.

Other participants used cognitive strategies rather than distraction, to reduce the attentional focus of pain. Maggie, a teacher with upper limb CRPS, found the addition of imagery similarly effective: “I used to imagine my pain as something I took and put in the bottom drawer, and I shut the drawer, and I was going to move on.” In other cases, distraction reduced the attention to the unpleasantness of desensitisation exercises. Roberta described how music could be helpful for distraction when completing painful desensitisation exercises, “I might put music on, and try and act like an idiot, just to have fun,” noting that “It doesn’t get rid of the pain, but I just think you need a goal to work towards to try and make it easier.” Desensitisation as a strategy aims to reduce sensitivity through repetitive provocative touch. Maggie described the desensitisation of her painful foot when saying, “I put a lining into the boot that was quite, well not rough, but you know mildly rough so that when I walked there was a little bit of abrasion on the skin and then I forced myself to go for a walk.” Unlike other strategies for symptom relief, desensitisation aims to lessen the sensitivity in the long term by provoking symptoms temporarily. Such strategies were typically provided by healthcare professionals and only maintained if they were perceived to either improve symptoms or move participants closer to their foundation values (e.g. the ability to wear hiking boots for hiking).

All participants searched for strategies that restored the use of their limb. Improving the functional capacity of their bodies offered an opportunity to return to meaningful activities, giving them a sense of control over their lives. Commonly, participants spoke about exercises in the form of graded physical activity. Chris described graded activity as “I was just told to build up, just minor, tiny bits. Just tiny, little, little bits.” The benefit of measuring and repeating tolerable amounts of activity meant the body could develop resilience to this activity. Rachel described her changes as “I just noticed the fitter I am, the stronger I am in the thigh, the better my pain is. I don’t know why, but it is better.” More importantly, restoring some pre-CRPS function offered psychological benefits as participants were moving more closely to the meaningful activities they enjoyed in their former lives:

> I started out with this, this really basic physio programme that they run that is just, like, you could even do it lying in bed, and it is basically engaging your core and doing a bit of movement and from that building up from that. Now I go to the gym a couple of times a week, and I walk 10,000 steps every day and, so being able to exercise again means I am losing weight. I feel a whole lot better. It really helps me mentally. (Megan)

For others, the decontextualised ‘physiotherapy’ exercises were not the most effective way to restore function. Roberta personified this love/hate relationship with rehabilitation:

> I make myself sit down every day and do those damn exercises though, even if it hurts. Like, I just think it's really important to try. I can't be one-handed for the rest of my life.

In these instances, focussing on everyday activities rather than specific rehabilitation exercises was better for improving their function. Roberta described her persistence to use her arm in meaningful ways:

> I had to get [a car] with all like the electric gadgets and stuff, so I don't have a big handbrake. Driving, I always made myself drive, even though I was told not to. But I still... even when I drive, I drive one-handed. I find it really hard using both my hands. So like, just having my right arm, trying to use it. It's kind of like, it's really gross. But I will make myself sit down and write, even if it's rubbish, because you know, I miss having my right arm.

By gradually increasing or adapting what they were doing, participants found they were able to build back meaning into their lives.

For those participants who drew connections between their experience of CRPS and their psychological state, improving psychological well-being became a focus of their management. The term ‘holistic’ was used to describe their overall health and well-being. Rose described holistic care as “focussing on the, on the mental and I guess the mental, spiritual, and social health of a person rather than just the physical.” Megan chose to use the term ‘Hauora[4]’ a Māori philosophy of health and well-being, to explain how she views her holistic self-management:

> It’s kind of recognising all the components, like not just paying lip service to what holistic looks like, but going actually what does this person got in their work quadrant, what have they got in their social quadrant. All of that whole Hauora, yes, is really important, I think. Because pain just leaches into everything doesn't it. And so, then the person has lost not only say function in the limb but their social life and their, their whole thing.

Improving psychological well-being was commonly targeted through what participants described as ‘self-care.’ For Rose, self-care was something that was perceived to support the pursuit of meaningful activities: “I think that if I don’t take care of myself, I will be back at square one, and I won’t be able to do the stuff I really enjoy.” Self-care was a process Rose developed throughout life experiences:

> I would start to manage my mental health by sort of, I guess, assembling tools to help with stress. Because I had experienced chronic stress growing up in high school and then university and so, it was sort of things like remembering to do little things I enjoy like, “you know what, I’m going to buy myself a coffee,” because it’s not a lot of money and I really enjoy it or it will be booking out some time to read a book or watch my favourite TV show or hanging out with my friends for a wee bit or that kind of thing. (Rose)

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[4] Hauora (holistic health and wellbeing) of Māori extends beyond disease and illness. In one Māori health model, Te Whare Tapa Wha, Hauora is achieved through: *taha tinana* (physical well-being), *taha hinengaro* (psychological well-being), *taha whanau* (social well-being) and *taha wairua* (spiritual well-being) Durie, M. (1998). *Whaiora: Maori Health Development*. Oxford University Press. https://books.google.co.nz/books?id=PQeKQgAACAAJ

Self-care was an individualised activity. For Rose, this included a variety of elements: “I would frequently exercise. I would have a good diet. I would get a good amount of sleep.” For June, a psychologist by profession, self-care was a question “What do you do to make yourself happy?” adding, “Not everyone thinks about how they make themselves happy.” Self-care was seen as a strategy for taking control of psychological well-being, often with the added benefit of improved symptoms, enabling participants to re-engage with pre-CRPS valued activities.

Recalibrating a New Pace of Life

The most agreed upon modification to take control was adjusting their pace of living. Every participant acknowledged that maintaining the pace of life, concordant with their pre-CRPS lives was not sustainable. This sometimes meant deconstructing part of their competitive personalities: “I’m a bit of a workaholic, I don't rest very well. It taught me a heck of a lot that” (Teresa). Many participants admitted difficulty in changing lifelong patterns:

> I had that mindset that if you’re not sweating like a pig, it’s not worth it, and I couldn’t do that. Like if I tried to do any exercise like that, I’d spend two weeks in bed. (Megan)
>
> You get through the kind of 'well, I'll beat you' sort of phase, and you really push ahead, but actually, that's an error of judgement. (June)

Part of their perspective shift in the journey towards living well was the recognition that their pre-CRPS modes of functioning needed to change:

> [Pacing yourself] was really, really hard to do. Really hard. When you’ve thought, when you have something that has been the way like it’s almost been a mantra, isn’t it? When you live your life a particular way, yeah, and then to go back and start from the beginning again and know it will take a really, really long time, but that little bit of change will make a huge change down the track, was huge. (Megan)

According to June, a new pace of life entailed “Not soldiering on… actually listening to your body.” For others, the idea of changing the pace of life was more nuanced: “patience” (Rachel); “to chill a bit more” (Teresa). For some, a new pace was prioritising and allocating a finite amount of energy or time: “You make your list, and you're ticking through your list” (Chris). For others, a new pace of life was the concept of restoring a balance by making consideration for their symptoms: “Tonight we've got a mate coming around for dinner, so you know I'm not going to overextend myself today” (Megan). Participants all learnt they needed to consider their symptoms before and consciously adjusting their pace during any activity.

Initially, altering the pace of daily life was perceived as a challenge due to its activity-limiting nature. However, once participants could see the value in consciously slowing down their activities, they were more likely to adjust their pace of life to control their symptoms. Chris reframed pacing to be positive rather than being associated with negative personal characteristics such as laziness or lack of motivation:

> I call it being on island time, but you're not really. You're not on island time because you're lazy, you're not on island time because you don't want to pick up more hours at work. You're on island time so you don't pop (Chris).

Participants described a paradoxical effect of monitoring their pace, whereby better symptom control allowed them to engage more in meaningful activities:

> Island time: it's not a state that nothing gets done. It's a state that because you can't go at full pace, don't try to make yourself. You just... but if you go at a steady pace, it's amazing what you'll get done. So it's that idea of not trying to push things, impossible things, that you just cannot like physically do in those timeframes (Chris).

Participants were more likely to sustain this slower pace of life if they perceived it moved them closer to restoring their sense of self. Chris added the positive impact on his family time, “In doing so, I found a nicer place, where I'd get home, and I still had something left for my family. I can listen and play cards with my kids instead of sitting on the couch.” Participants unanimously emphasised the importance of changing their pre-CRPS pace towards a life of consideration and adjustment to their pain. Adapting their pace of life was the easiest way they could learn to take control.

Taking Control in a Seemingly Uncontrollable World Summary

People the world over live with chronic conditions. You do the best that you can but that… just because your body is not perfect it doesn’t mean to say your life can’t be great. My life is pretty great! (Maggie)

Participants expressed a need to use tools to take control and self-manage their condition. Taking control was commonly initiated through the support of experienced healthcare professionals who valued building a therapeutic relationship. However, many also developed self-management strategies through self-discovery or listening to others with CRPS. Participants used a range of tools that offered symptom relief, restored function or improved psychological well-being. Notably, there was minimal consensus on which strategies were useful; rather, participants valued a trial-and-error process to determine which strategies they retained. The most common strategy was the adoption of managing the pace of life and prioritising activities of living. Such strategies were maintained, despite their difficulty, if they were perceived to take them closer to restoring meaning and purpose in their lives.

Theme Three: Rebuilding a Purposeful Life with a New Identity

I lost everything. Like, I lost my job and stuff. So, to just try and rebuild that has been quite difficult too. (Roberta)

The third feature of the journey to living well *with* CRPS was the rebuilding of purpose and meaning within a new post-CRPS identity. Coming to terms with a new identity required participants to become more accepting of the impact of CRPS on their lives. Purpose and meaning were developed through the restoration of pre-CRPS activities and the exploration of new post-CRPS activities. Pre-CRPS activities were reconstructed through accommodation and adaptation, whereas the new post-CRPS activities were explored through open-mindedness and exposure. Participants actively developed a new identity by restoring and rebuilding meaningful activities, thus providing purpose and restoring their sense of self.

Accepting My New Life With CRPS

The final perspective shift in the journey to living well *with* CRPS was the active decision to focus on restoring purpose over pain elimination. Participants recognised this was the result of a journey, reflecting on the significant effort spent on pain elimination post-diagnosis. Chris used the term ‘embattlement’ to describe the all-encompassing and all-consuming nature of searching for the cure:

> So, as you unravel the ball, the more embattled I got, the harder it is to work out that anything helps you.

Paradoxically, the more energy they used to eliminate pain and resolve their condition, the further they moved from the foundations of their identity that contributed to their sense of self. Through time and failure to resolve their symptoms, participants recognised their efforts were largely futile. In their current lives, all participants accepted that pain was going to be a part of their futures: “It's always there. It never, ever, ever goes away” (John); “It would be nice if it would go away, but it’s not going to” (Maggie); “Can't change it. Can't make it go” (Chris). John described his “main thing,” as “the fact I've accepted that it probably will never go away.” He offered advice to others, nicely summarising pain acceptance as the stepping stone to living well:

> But if they can actually accept that it's going to be there for the rest of their life, they can then build their life around it. Different, but they can build their life, and get on with their life, and still be productive and everything else like that.

Accepting that pain would be a feature of their lives moving forward was the most significant step for participants to rebuild a new purposeful life.

However, living well *with* CRPS was not simply about accepting a life of pain. Pain acceptance was the determination that certain aspects of life were worth experiencing pain for. The transformation to living *with* CRPS was the active decision to use the energy previously directed towards pain elimination to pursue rebuilding a new, purposeful life. Megan articulated the shifting perspectives in acceptance:

> I think then deciding to use the energy that I had for things that I was passionate about would help me feel more of a sense of purpose. So, I've got these two part-time roles that I really like. So, I'm working with a really good friend in one, and I'm working with a bunch of people that I really get along with at the pain service. So that's been really, having that again, has been really helpful.

Through developing pain acceptance, participants were more willing to experience pain, negative feelings or fear if it meant they were engaging in activities that gave them meaning and purpose. For June, re-engaging with fearful activities such as hiking outweighed the risk of falling:

> I was a bit worried about tripping at times, but, you know, that was minor in comparison to the benefit of being out and about.

Choosing to pursue rebuilding a purposeful life through the restoration of meaningful activities was the active process towards restoring a new sense of self and living well *with* CRPS.

A unique feature of living with CRPS was navigating the complex emotional relationship people had with their painful limb. Accepting and moving forward in their lives required reconciliation with their limb. For June, rebuilding the positive relationship with her hand included reframing her perception of pain:

> And being able to step aside from it, being able to look at it from a distance. Not so much feel the pain and do it anyway but feel the pain but understand it differently. You know what I mean? So that it's not just your body being really unhelpful. But I suppose when you start seeing it as a nurturing thing that your body is doing, it's kindness, not an aggravating factor.

Rachel's relationship with her feet remained complex despite reconciliation. Throughout the interview, she often maintained disconnect by referring to her CRPS foot as 'it': "hated it and it was ugly." However, she added she was working on rebuilding the relationship through affirmations, even tattooing her feet to represent her children:

> I do try to that positive self-talk where I go, "Oh my feet are so beautiful." In fact, I've put a tattoo on one of my feet which is a flower. And I'm the flower, and I've got three koru for my three children kind of things. So it's a positive thing, and people say, "Oh, how are your feet?" and I say, "Well, they take me where I want to go."

Roberta continued to struggle with strong feelings of "disgust" towards her arm, describing ongoing features of body perception disturbance, "you feel guilty because you feel like it's not an arm to use." Roberta demonstrated that living well *with* CRPS was not a matter of resolving these complex emotions but instead maintaining persistent positive behaviours toward rebuilding their life alongside their limb:

> I try and use my right arm as much as I can, put it that way. Some days I'll use it a lot more than other days. Some days, I don't want to go near it; it's gross. So, like, every day is an argument, really, with my own body.

Due to the ongoing presence of a limb, neglect or disuse of a limb is not a sustainable long-term strategy; therefore, participants had to learn to rebuild a positive relationship with their limb to move on with their lives.

Maintaining hope was seen as both a facilitator and a barrier to living well. For some, hope their condition might improve was the ongoing motivation to maintain self-management. Chris described hope as “everything.” He added, “Because without hope, you're hopeless.” He communicated the idea of ‘retaining hope’ as a motivator that his life will change:

> You had that hope, and you go to yourself, "Okay, I can't do everything I used to do. So what can I do that I'll enjoy that's different?". You just have to do that. And there is a chance, and I think that's the thing when I say 'hope,’ there is a chance that it will one day come right. You know? That's the best hope you can have.

Importantly for Chris, retaining the hope his CRPS would improve was not a barrier to him pursuing meaningful activities. In other cases, hope was contradictory to acceptance. In such cases, placing your life on hold or ‘waiting in hope’ until your situation improved was a barrier to pursuing life and living well. John described this concept of ‘waiting in hope’:

> If somebody had said to me right from the word go, "John, this is what you're going to have for the rest of your life. You're going to have to expect pain, discomfort, and you are the only person who can work around it". It's a solid fact, then, that you know you're going to have the rest of your life. You then don't hold onto that fantasy that one day you're going to wake up and it's gone because that does not happen. So then you accept it and say, "I've got it, alright?”

All participants recognised the importance of accepting that CRPS was a part of their future lives. They articulated the importance of rebuilding a purposeful life *with* CRPS, yet, paradoxically, many hope their condition would improve given enough time. John, previously in opposition to hope, went further to describe the ‘hope’ a spinal cord stimulator may improve his situation:

> Well, see, with mine, now I've got a hope that if they put that in, it will relieve the pain. It doesn't relieve it permanently. It's a temporary thing only. Now, I might say to myself, "God, I can be in pain relief for a week or pain relief for an hour. Oh, that'd be glorious". It's not saying it's going to go away permanently.

Therefore, acceptance was perceived not as a terminal endpoint but rather as a process that has conditions. Whether it be a spinal cord stimulator, a new medication, or the success of self-management, participants viewed ‘accepting’ as the active decision to pursue rebuilding their life, even whilst retaining some hope their situation would improve.

Rebuilding Purpose and Meaning

Participants described rebuilding purpose and meaning by maintaining and restoring some of the activities they lost due to the disruptive impact of CRPS. It is important to note that restoring pre-CRPS meaningful activities was not simply an exercise in mind over matter; instead, participants used adjustments and accommodations to focus on living a full life *with* symptoms. Megan described the process of rebuilding life around her pain:

> So when you decide to organise your life around [CRPS], and so you're not saying no to something; you're saying yes to something else. It is a really, has been a really helpful construct. So, deciding what are the things you want to achieve, like how do you have a full life even though you have pain.

Many of the participants described the rebuilding through adjustments and accommodation. Chris explained the adjustments he made to pursue his family-focused values:

> It's being able to actually at the end of the day, be able to concentrate when your kids are talking to you. You know, being part of their lives. Like, I go to their sports, I've got my bung arse chair I sit on. So I've got just like one of those little fold-out, like mini fold-out chairs. So games, watching the kids sports, you know? That's pretty massive, the kids knowing that I care.

Accommodations ranged from creative to less desirable but ultimately offered participants an option to retain aspects of pre-CRPS passions:

> I want to get a drone, so that we can go fishing again, using a drone. (John)
>
> I'm doing a dog showing with the Shepherd, I've got to get somebody else to handle it. Or I walk around or run around as much as possible around the outside, so I'm still participating. (Paul)
>
> Having my meal cut up by my husband is not my favourite, but you know, it meant we could go out for dinner. (June)
>
> Because the first time, my kids, we went to the museum, and that was a while ago. And that was so hard I was embarrassed, and all that sort of stuff, but I went anyway, and it was tough. At Rainbow's End, I had my chair. When we got to queues, I'd just sit down on the chair, you know? But I was there, and we went and did it and we had a great day. So it's being able to do stuff with my kids. (Chris)

The fundamental strategy behind rebuilding purpose and meaning was using adjustments and accommodation to live a full life even though one has pain. Where restoration of pre-CRPS activities was not physically possible, participants shifted away from worrying about the form of the activity to simply engaging with the function. Engaging in these activities gave participants a sense of fulfilment and brought them closer to restoring their sense of self.

Unfortunately, despite adjustments and accommodation, some pre-CRPS activities were not sustainable. Letting go of some pre-CRPS aspirations was challenging but opened the door to new goals and joys. Chris added, “You have to find other ways of doing things, and you've got to find your joy elsewhere.” Alternate joys offered a similar sense of fulfilment without the physical burden:

> I can still do stuff. Like, I can't walk down the whole Cook's Beach. Can't walk more than 650 metres or so in a go, you know. I really don't have stamina. But when my daughter wanted to learn how to surf, like, I took her out there to show her how to do it. Because I could still swim, right? Swimming is something I've been able to do. Like, weaker leg, I've got two good arms and a foot. So you just work out what you can do as best you can. (Chris)

> If we could go [ocean] cruising, that replaces, say, doing me fishing, or doing the maintenance, or doing something else. (John)

Participants were required to ‘make room’ for the condition in their future self. Making room entailed ‘letting go’ of less important or unsustainable parts of their pre-CRPS lives. The end product was participants maintaining a full life alongside their painful limb.

Reconstructing a New Post-CRPS Identity

The impact of CRPS stripped the foundations of participants’ sense of who they were, disrupting their sense of self. As documented in the ‘Living *against* CRPS’ introduction, the impact of CRPS was characterised by the disruption of their personal and social identities, causing an existential revisiting of purpose. Throughout the interviews, participants identified that deconstructing and reconstructing their pre- and post-CRPS identities offered them an opportunity to redefine themselves. For Megan, the diagnosis of chronic pain offered an opportunity to work with others starting their journey:

> I love working for the pain service. I love my role there. I’m working with a bunch of people that I really get along with at the pain service. So that’s been really, having that again, has been really helpful.

In some cases, people outwardly described a sense of post-traumatic growth, including a newfound appreciation of life post-CRPS. For Chris, the forced change in personality from a “high achiever” and “mega-driven” permitted him to slow down and appreciate those features of life previously taken for granted:

> I've kept my job, and I love my job. And I now work in a creative area of the school. So yeah, my life's changed, and I don't. To be honest, I wouldn't want it to go back to what it was because that was too frantic as it is. I've got to say, because of it, my life is a shit tonne better than it was two years ago. Like, is it the life I had before this? No. But is it bad? No. Is it fun? Yeah, I've got some pretty cool shit.

Rose viewed the impact of CRPS from a strength-based lens, seeing change as offering a greater balance in a life less dominated by pain:

> I guess in my mind, as well, it kind of gave me an excuse. I mean, there should never be an excuse to take care of yourself, but in my mind, it was a bit more of an excuse to be a bit more selfish almost. Kind of like, "No, I need time off. I'm taking time off for myself." I'm not worried about what people are going to say.

For Roberta, living with CRPS offered a deeper sense of empathy for the struggles of people navigating the healthcare system. Her experiences formed the motivation to go to medical school to help those starting their journey:

> I'll really use my physio degree to get into medicine and then become an musculoskeletal specialist. I think that'd be really cool. I just feel more compassionate about getting other people through it too.

Whether it be a deeper sense of empathy or an excuse to appreciate the features of their current lives, people living well *with* CRPS used the reconstruction of their identity as an opportunity to add further purpose and meaning to their lives.

One unexpected feature of people living well *with* CRPS was the explicit rejection of being defined by the label. Using various words, almost all participants emphasised an unwillingness for CRPS to be a defining feature of their identity. June described the choice to bolster a broader, more full life identity not defined by CRPS:

> Well, that you're more than your hand, or the pain, or whatever else that you've got CRPS. There's a life that you live outside of that. You know, you have children, and a husband, and work, and things like that. You know, just knowing you in the round really.

For all participants, living well *with* CRPS was about living life, not living a condition. Teresa personified this statement when saying, 'It doesn't define me':

> It's who you are, and it defines you as the person who you are. But actually, I became a better person.... It doesn't define me. (Teresa)

Although Megan began working within a chronic pain service, arguably strengthening a post-pain identity, she emphasised the importance of the role for restoring her previous caring values as an antenatal educator. Importantly for others, this was not a matter of shame or denial but rather an acceptance of their situation and recognition that they are more than just people with CRPS:

> I'm not ashamed of having CRPS at all, I'm not embarrassed.... So like, just trying to get people to like actually understand it's alright to be different. I think that's probably the main thing that people need to actually understand – that it's okay. (Roberta)

The position of living well *with* CRPS took resilience and persistence. The participants reflected on the journey and adversity it took to reach their point of living well. Roberta documented the daily battle with symptoms and the resilience and determination it took to restore a fuller life identity in the face of adversity:

> Not to give up. Just don't give in. It's really hard, but you've got to. As soon as you wake up in the morning you've got to get up and try and live your life. Like, you really have to. What is the point? You've got one life. You're not going to get it back, so you might as well just try and live it the best you can. And if you trip up, it's okay; you're only human.

Many acknowledged adopting this stance was not possible early in their journey. Living *against* CRPS contradicted the notion of rebuilding a broader and fuller life, instead focussing on relieving symptoms. Through their journey, they shifted focus to rebuilding a new life with a new identity. In conjunction with the introduction ‘Living well *with* CRPS: the restored self’, these examples form the basis of rebuilding a life of purpose and meaning alongside their painful limb.

Rebuilding a Purposeful Life With a New Identity Summary

> *Changing your lifestyle, like, my whole lifestyle has changed with this. And it's different, I enjoy it, but it's different.* (Chris)

Rebuilding a purposeful life with a new identity was the product of accepting the long-term nature of CRPS whilst actively deciding to use their energy to restore the foundational values of their former selves. As noted, accepting their situation was not a matter of a willingness to experience pain but rather a decision that pursuing life was worth experiencing pain for. Many participants restored parts of their pre-CRPS lives through accommodation and adaptation, whilst others explored new activities and joys by remaining open-minded and curious. One feature of this cohort was the reluctance to be defined by the label ‘CRPS.’ Participants demonstrated a desire to be defined by a broader, fuller life identity whilst not downplaying the resilience and persistence that they had to get there. Rebuilding a purposeful life with a new identity was the final step in restoring ones sense of self and living a life of purpose and meaning alongside CRPS.

Chapter Four Summary

Living well *with* CRPS was the product of a journey. The initial stages of living *against* CRPS were characterised by symptom dominance, navigating an unhelpful medical system and searching for a cause or reason for their incapacity. The all-encompassing daily struggle eroded the foundations of their identity, disrupting their wider sense of self. Participants initiated their journey of changes with a perspective shift catalysing the mindset changes required to live alongside their condition. The journey was defined by three themes: ‘Making sense of my new life with CRPS,’ ‘Taking control in a seemingly uncontrollable world,’ and ‘Rebuilding a purposeful life with a new identity.’ Individuals used sensemaking processes to understand the diagnosis and its impact on their wider sense of self. Using this knowledge, they developed tools and self-management strategies to begin to take control and rebuild their lives post-CRPS. Restoring their sense of self was achieved by accepting their situation and the active decision to focus on rebuilding their post-CRPS lives through adaption and accommodation. Living well *with* CRPS was defined as having restored a sense of purpose, meaning and new identity, accepting the focus on living alongside their painful limb.

Figure 10

The Journey to Living Well With CRPS Illustration

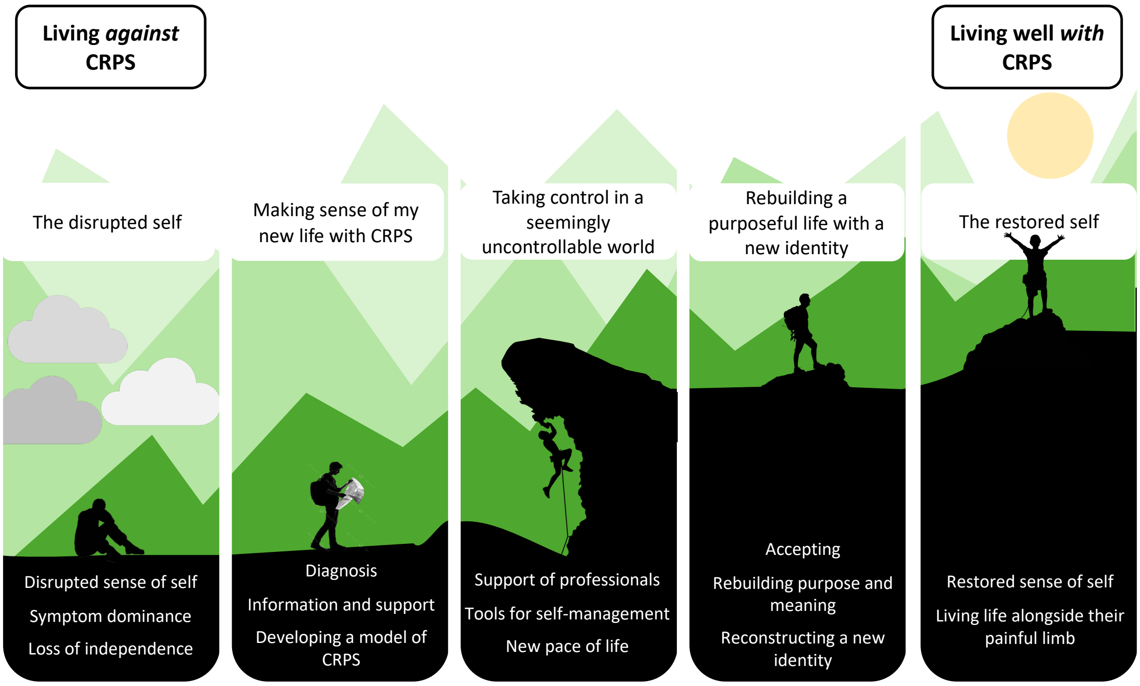

Table 5

Themes, Sub-themes, and Supporting Data

Theme	Subtheme	Summary quotes
The journey from living against to living well with CRPS	Living *against* CRPS	I think that everyone searches for some sort of purpose and passion and for a long, long time I'd had this job that I absolutely loved. That people absolutely loved me when I was doing it. So, not only did I lose that I also lost the psychological income that came with that. So, I felt quite worthless. I felt like I wasn't pulling my weight in our relationship. (Megan) I've fished all my life, and then suddenly to not have it, it was real ... And also, the fact that, alright I can't work on the cars, I can't do as much. I used to a lot of woodwork and make things, and everything like that. I had a big workshop. And, I mean, I couldn't do that. And that is a sort of big loss, that part is. (John)
	The perspective shift	So I was like if anyone's going to help me, it's me. I'm the only one who can dig myself out of my hole. It's not what I caused for myself, but it doesn't matter how it occurred or anything like that. I just had to have that moment where I was just frustrated beyond belief, and just went, "I'm not going to... this isn't going to be my life." You know? I'm not going to allow this to be me. (Chris) First up I had to decide to get myself out of the way. Because I thought I knew better and continuing to think that way was not going to allow for any change and so, you know if you continue to do the same thing, you're going to get the same result. (Megan)
	Living well *with* CRPS	Being able to do, yea simple things, like being able to go to a restaurant with friend or being able to drive to a friend's house to have dinner with them. That freedom part is really, really valuable and as long as I can take care of myself, again in that holistic way, I can know that I can achieve that freedom and that it's completely possible. (Rose) So, for me [living well] looks like being someone who can participate well with my life. By that, I mean I have a social life, I have a sporting life, I have a love life, I have a family life. I have hobbies, you know. (Megan)
Theme 1 - Making sense of my new life with CRPS	Making sense through a diagnosis	I didn't know about CRPS, to be honest, and I think it's quite a secret squirrel society almost. So, actually having a label enabled me to do some looking and thinking and reading, and researching, and getting information about pain, and management. (June) Mainly just like knowing I wasn't going insane. Like, I was saying, like, I was in so much pain, and people were like, "You're just being a drama queen, it's in your head". And to know it's not in my head. So just like getting that diagnosis was like, hallelujah. (Roberta)
	Making sense through information and support	I think its that's ability to quickly form a rapport and have that, to make connect quickly so that those people feel heard and seen and so importantly not alone. Often you'll find that people sort of relax at that point, it's like they've found their tribe. These people that they don't have to explain what living with pain is like. There is something wonderful about that. (Megan) I mean, pain is so nebulous, you know, people just don't know what that looks like. And actually just trusting when someone is saying to you, "This is really painful for me". So I think actually, sharing that information, which I did, and I think that really, really helped. My partner understood. (June)
	Making sense through an evolving conceptual model of CRPS	That was the real key. The key milestone in understanding that my health, for me, it's very holistic. So, the way that I'm like there's the whole thing about fight and flight and being permanently in that elevated state due to stress and if I'm in that state for long enough, changes are going to manifest in my body and in my physiology. Which is probably, partially, why my CRPS has developed over the last few years. So, sort of understanding that for me everything is, it's very connected. (Rose) I think it's very much that your brain's being very kind to you, and it slams on the protective nature, but hasn't taken the levers off. And so it's really saying, just be really, really careful. (June)

Theme 2 – Taking control in a seemingly uncontrollable world	Taking control with the support of professionals	I guess for me good support was just sort of, listening if [I] needed to vent. Because sometimes I would just get super frustrated and be like “I’ve had enough of this.” I need to just verbally vent to someone, people who would listen. They would listen, they would understand, and they wouldn’t necessarily hand out advice, like things like “Have you tried Panadol? Have you tried Ibuprofen?” and I’m like “yeah, yeah I have.” (Rose) I appreciated they saw me as a person. They knew what CRPS was, and they were understanding of that. More than understanding, they really got it, and they could talk to it, you know, and look at the weird and wonderful things my hand was doing, and accept it. (June)
	Taking control by evaluating tools for self-management	I started out with this, this really basic physio programme that they run that is just, like, you could even do it lying in bed, and it is basically engaging your core and doing a bit of movement and from that building up from that. Now I go to the gym a couple of times a week, and I walk 10,000 steps every day and, so being able to exercise again means I am losing weight. I feel a whole lot better. It really helps me mentally. (Megan) It’s kind of recognising all the components, like not just paying lip service to what holistic looks like, but going actually what does this person got in their work quadrant, what have they got in their social quadrant. All of that whole Hauora, yes is really important I think. Because pain just leaches into everything doesn't it and so, then the person has lost not only say function in the limb but their social life and their… their whole thing. (Megan)
	Recalibrating a new pace of life	[Pacing] was really, really hard to do. Really hard. When you’ve thought, when you have something that has been the way like it’s almost been a mantra, isn’t it? When you live your life a particular way yeah and then to go back and start from the beginning again and know it will take a really, really long time but that little bit of change will make a huge change down the track, was huge. (Megan) Island time, it's not a state that nothing gets done. It's a state that because you can't go at full pace, don't try to make yourself. You just... but if you go at a steady pace, it's amazing what you'll get done. So it's that idea of not trying to push things, impossible things, that you just cannot like physically do in those timeframes. (Chris)
Theme 3 – Rebuilding a purposeful life with a new identity	Accepting my new life with CRPS	But if they can actually accept that it's going to be there for the rest of their life, they can then build their life around it. Different, but they can build their life, and get on with their life, and still be productive and everything else like that. (John) I think then deciding to use the energy that I had for things that I was passionate about would help me feel more of a sense of purpose… So, I’ve got these two part-time roles that I really like. So, I’m working with a really good friend in one and I’m working with a bunch of people that I really get along with at the pain service. So that’s been really, having that again, has been really helpful. (Megan)
	Rebuilding purpose and meaning	So when you decide to organise your life around [CRPS] and so you’re not saying no to something, you’re saying yes to something else. It is a really, has been a really helpful construct. So, deciding what are the things you want to achieve, like how do you have a full life even though you have pain. (Megan) So for me, like, it's being able to actually, at the end of the day, be able to concentrate when your kids are talking to you. You know, being part of their lives. Like, I go to their sports, I've got my bung arse chair I sit on. So I've got just like one of those little fold-out, like mini fold-out chairs. So games, watching the kids sports, you know? That's pretty massive, the kids knowing that I care. (Chris)
	Reconstructing a new post-CRPS identity	Well, that you're more than your hand, or the pain, or whatever else that you've got CRPS. There's a life that you live outside of that. You know, you have children and a husband and work, and things like that. You know, just knowing you in the round really. (June) It's who you are and it defines you as the person who you are. But actually, I became a better person... It doesn’t define me. (Teresa)

Chapter Five: Discussion

This study aimed to understand the meaning of, and process towards, living well with CRPS as described by individuals who self-identify as living well. No other study has explored the concept of living well with CRPS. These novel findings suggest that living well with CRPS is defined as having restored a sense of self by focussing on living alongside their painful limb. The overarching theme emphasised that living well was the product of a journey emanating from living against CRPS, a stage characterised by symptom dominance, the search for a cure, and the disruption of one's sense of self. Participants described navigating the journey through processes of making sense, taking control, and rebuilding a purposeful life with a new identity. This chapter will discuss the findings in the present study, examining them in the context of current literature. The chapter will finish with a discussion of the implications, limitations and directions for future research.

The Disruption and Restoration of One's Sense of Self

This study revealed that living well with CRPS was the product of a journey. These findings suggest that people living with CRPS do not automatically assume the position of living well; instead, living well requires an active process with significant life modifications. The first step in the journey to living well was the recognition that CRPS disrupted one's self of self. We termed this phase 'living *against* CRPS.' The loss of self has a long history in chronic illness (Charmaz, 1995) and chronic pain research (Bury, 1982; Morley & Eccleston, 2004). Charmaz (1995) suggested that any chronic illness will undermine the unity between the body and self, causing a change in one's identity. Bury (1982) further described chronic pain as a "form of biographical disruption" (p. 16), noting that pain disrupts one's career aspirations, one's personal life meaning and expectations, and thus one's personal biography. Therefore, people living with disruptive chronic pain are forced to reexamine their sense of self (Morley & Eccleston, 2004). Within the CRPS literature, the loss of self is discussed in the context of identity (Antunovich et al., 2021), intimate relationships (Packham et al., 2020) and social support (Rodham et al., 2013). This study supported the breadth of literature indicating that CRPS and chronic pain impact not only day-to-day function but rather erode the fundamental aspects of one's identity, disrupting one's sense of self.

The participants in this study defined living well with CRPS as the restoration of their sense of self by rebuilding purpose and meaning in their lives with the focus on living alongside, in partnership with, their painful limb. These findings mirror the meta-ethnography by Francine Toye and colleagues (2021), who described the 'healing journey of chronic pain' as the 'reconnection with one's self.' In the theme 'I am reconnected with myself,' the authors summarise, "Pain is not my identity. I am still me. Pain is part of my life experience. I am living alongside pain. It no longer dominates me. Pain is just there… I have reengaged with who I am: my core self. I have restored my sense of self. I am at peace" (p. 1339). The process of adjusting whilst renegotiating one's self-concept has previously been documented in living well with chronic pain research (Lennox Thompson et al., 2020). The participants in the present study found renegotiating their new post-CRPS self was easier when they could view the positive aspects of their identity shift. Whether it was a change in career, an appreciation of family, or an excuse to put one's needs first, many of the present study's cohort reflected on their journey in a way that was consistent with post-traumatic growth (Tedeschi & Calhoun, 2004). The present study found that people who are living well with CRPS developed positive psychological adaptations after diagnosis, supporting them in rebuilding their life with a new identity. Voorhees (2023) recommends that pointing out positives in those with pain-related identity shifts can foster hope and strength, allowing people to develop an appreciation of life post-pain-onset. Supporting people to a new post-CRPS self has implications for healthcare professionals; this will be discussed more in the Implications section.

One unexpected finding in the present study was that all participants actively chose to reject the CRPS label as a defining feature of their identity. This finding differs from the early work of Pincus and Morley (2001), and Morley et al. (2005), who both suggest the disruption of chronic pain causes the overlapping or 'enmeshment' of the schemata of pain, illness and self. Smith and Osborn (2007) termed this new identity 'self with pain,' which may account for the 'illness identity,' as described by (Charmaz, 1995). One difference for the current cohort may be the inclusion criteria of individuals who self-identify as living well. In a similar study, Lennox-Thompson (2015) recruited individuals living well with chronic pain, noting their participants "reject the label of patient, or disabled and consider themselves to be 'people'" (p. 20). The authors found participants preferred to "carry on with their daily life rather than identify particularly strongly with a chronic pain label" (p. 14). Voorhees (2023) hypothesises that people accept illness-related identity changes in different ways, some by "rejecting the label of passive victim and adopting an identity of competent actor in control of her own story" (p. 1649). There are no data exploring the illness-related identity changes in CRPS; however, one qualitative study of Korean people living with long-term CRPS noted that people deliberately hid their diagnosis due to fear of stigmatisation or 'being seen as strange' (Kwon & Kim, 2021). The present study identified that people living well with CRPS did not align with a CRPS-illness-identity, not due to fears of disclosure, but rather a stronger desire to be defined by a fuller life identity. Lennox Thompson et al. (2020) propose that living well with chronic pain requires individuals to achieve self-coherence whilst they renegotiate their self-concept. The present study supports this idea, finding that individuals who live well with CRPS have a strong sense of coherence, thus actively rejecting the CRPS-illness-identity, preferring to be defined by their own clearly defined self-concept.

A common feature of CRPS research is the disconnect between the painful limb and the person living with CRPS (Brun et al., 2019; Lewis et al., 2007). Several of the participants in the present study described negative emotions and, at times, a feeling that the limb was not theirs to use. In such instances, living well with CRPS requires people to reconcile their limb detachment by reframing a positive relationship with their body and pain. Body perception disturbance is considered to involve feelings of disgust towards the limb, incongruence between sensory and visual information about the limb, disturbed position sense, difficulty using the limb and a desire for amputation (Brun et al., 2019; Lewis et al., 2007; Lewis & Schweinhardt, 2012). Some authors proposed these perceptual changes are related to visuospatial attention bias (Moseley, 2005) through cortical level changes (Di Pietro et al., 2013). However, more recent clinical trials have demonstrated no evidence for visuospatial bias (Filippopulos et al., 2015; Ten Brink et al., 2021) with contradictory findings on cortical changes in CRPS (Mancini et al., 2019). One CRPS study hypothesised that people mentally detach themselves from their painful CRPS limb as a protective psychological strategy for their personal and social identities (Antunovich et al., 2021). In an IPA featuring people living with chronic low back pain, Osborn and Smith (2006) identified that people fracture their bodily experience, excluding the painful body part from their self-concept. Rather than interventions targeting visuospatial information or cortical reorganisation, this study supports the notion that we should ‘reconnect’ a painful limb by targeting emotional responses towards the limb, fostering self-compassion and restoration of one's sense of self.

Making Sense of CRPS

This study found that people need to make sense of CRPS as a diagnosis to begin the journey towards living well. The participants described a diagnosis as the articulation of the unknown, validating their suffering in a world of stigmatisation. Clarke and Iphofen (2008) described a diagnosis as removing the cloak of invisibility, validating people’s experience of chronic pain. Bullington et al. (2003) further portrayed the medical journey as creating ‘order out of chaos,’ noting that a medical diagnosis was often the first step in moving from chaos to meaning. However, the present study also corroborated earlier studies identifying that a ‘chronic pain’ diagnosis such as CRPS was not always well received. A qualitative study exploring the impact of ‘chronic pain’ as a diagnosis found that the diagnostic label may elicit feelings of uncertainty as if providers are suggesting their diagnosis was ‘not real’ (Neville et al., 2019). Moreover, uncertainty often causes a relentless search for a more coherent diagnosis (Neville et al., 2019). Several CRPS studies have demonstrated that despite receiving a diagnosis, many continued to make sense of their condition, pursuing efforts to self-inform (Beales et al., 2021) and often making their own explanations for their symptoms (Antunovich et al., 2021). A cross-sectional survey of people with CRPS demonstrated that individuals with a poor understanding of their condition also experienced greater pain, disability, and kinesiophobia (Antunovich et al., 2020). Sensemaking, therefore, aims to find coherence, understanding and meaning (McCracken & Scott, 2023). The present study identified that explanations that lacked coherence were rejected aligning with prior sensemaking research, which determined that people make sense of their pain through diverse, inconsistent conceptualisations often dissonant with traditional pain neuroscience education (Keen et al., 2021). This finding could support clinicians by empowering their patients to guide sensemaking instead of providing didactic generic pain neuroscience education.

The findings in this study are congruent with much of the lived experience CRPS research that emphasises the need to make sense (Beales et al., 2021) and often uses terms such as 'becoming informed' (Rodham et al., 2013) and the 'need to be an expert' (Grieve et al., 2016). Yet, like many of these studies, the participants in the present study felt uninformed after their diagnosis. According to an early survey study by Brunner et al. (2010), only 6% of the 101 participants diagnosed with CRPS understood the minimum medical knowledge related to the condition. Additionally, further qualitative CRPS studies have found that accessing reliable and trustworthy information was challenging for people with both acute (Griffiths et al., 2023a) and long-term CRPS (Grieve et al., 2016). This study found that many people chose the Internet to seek information first, confirming the findings of a similar study by Beales et al. (2021) who described the information online as both "confusing and confronting" (p. 399). In a systematic review of available online information, Moore et al. (2021) found that 57% of the information available from credible sources was inaccurate or unclear. The same research group conducted an e-Delphi study to determine the core educational concepts for people living with CRPS. Moore et al. (2022) consulted 7 healthcare professionals and 55 people living with CRPS, finding the most commonly agreed upon themes were CRPS does not define you, the importance of sleep and rest, the importance of sleep hygiene, having a supportive medical team, and information to provide your family. Many of these themes parallel the findings in the present study, except for the addition of sleep. One important feature of the study by Moore and colleagues (2022) was the lived experience group determined 'lived experience,' 'mindset,' and 'social factors' as very important, whereas the healthcare professional group determined 'prognosis,' 'diagnosis,' and 'mechanisms' as very important. This difference suggests healthcare professionals strive to understand the pathogenomics of the disorder, whereas individuals strive to learn to cope with the disorder. This may be one hypothesis as to why the knowledge gap remains and why some explanations of CRPS lack coherence for those living with the condition. More importantly, this stresses the significance of studies such as this, which feature the voices of those living with the condition, to guide future healthcare interventions designed by consumers and healthcare professionals. As best practice clinical guidelines stress the importance of information and education (Goebel & Turner-Stokes, 2018; Harden et al., 2022) further research into how people make sense of CRPS and its impact on their lives should be a priority for future efforts.

This study demonstrated the critical role that supportive social connections can have on an individual's journey to living well. Positive social support was facilitatory, whilst no social support was deemed a barrier towards living well with CRPS. The findings support previous CRPS lived experience studies that illustrated the crucial role partners and loved ones played in intimate (Packham et al., 2020; Raja et al., 2021) and non-intimate relationships (Johnston-Devin et al., 2021; Rodham et al., 2013). Family support is essential for people living with CRPS, yet stigma, disbelief and invisibility of pain are common in the responses of friends and family (Johnston et al., 2015). Other studies stressed the importance of finding support outside of the family (Johnston-Devin et al., 2021). The present study findings suggest that meeting other people with CRPS offered a sense of validation and an opportunity to discuss their problems without burdening family and friends. Additionally, various pain management programme studies conclusively describe the group context as a positive feature in their management (Johannesson et al., 2023; Rodham et al., 2012). There are no studies exploring the role of peer-support models in CRPS. Such peer support and lived experience coach models are commonplace in mental health (Shalaby & Agyapong, 2020) with more recent chronic pain studies demonstrating positive feedback of patient-led peer support groups (Farr et al., 2021).

However, the participants in this study also articulated the fine balance of moderating negative peer support. All of the cohort avoided online support groups noting such groups commonly triggered negative experiences and often provided misleading information. This finding contradicts earlier studies exploring the role of online support in CRPS communities (Rodham et al., 2009; Smedley et al., 2015). Online communities provide an easily accessible option where people who usually feel isolated can feel understood (Rodham et al., 2009); however, as Smedley et al. (2015) found, most of the support provided online is emotional rather than information and networking. One, therefore, would need to consider the function of seeking support online. For those living well with CRPS, social support was primarily for pragmatic reasons, such as sharing information and management strategies. For others, groups may offer a place to express negative feelings toward healthcare professionals, or 'venting,' as it is referred to online (Rodham et al., 2009). According to Tankha et al. (2023) chronic pain groups may reinforce an 'us' versus 'them' mentality, strengthening their identities with chronic pain. As discussed earlier, individuals living well with chronic pain are more likely to reject the label of 'patient,' therefore one assumption may be that those living well with CRPS may want to restrict their interactions with individuals who are seeking to strengthen their identity with CRPS. For those beginning their journey, online groups and the ability to 'vent' may serve a valuable function, but importantly, this function may shift over time. Further research exploring the varying functions of support groups may help further guide the development of resources for those seeking social and pragmatic support.

Taking Control

This study found that accessing a healthcare professional who had experience, demonstrated empathy and prioritised building a therapeutic alliance was beneficial for people taking control of their condition. However, like much of the CRPS literature, finding a healthcare professional with experience was challenging (Griffiths et al., 2023a; Rodham et al., 2012; Rodham et al., 2013). A 2019 survey of international clinicians and academics by Grieve et al. (2019) found that nearly half of their cohort struggled to recognise the symptoms of CRPS. For many in the present study, accessing experienced healthcare professionals was often only through tertiary or specialist services. Like previous qualitative CRPS research, experienced professionals gave study participants the confidence they were managing their condition appropriately (Rodham et al., 2013). The benefits of healthcare professionals who listened and demonstrated better interpersonal skills were also common themes in the CRPS literature. Notably, finding those who treated the whole person not the condition (Griffiths et al., 2023a; Raja et al., 2021), who provided honest and simple language explanations (Beales et al., 2021; Grieve et al., 2016; Griffiths et al., 2023a), who demonstrated empathy, listening and understanding (Beales et al., 2021; Griffiths et al., 2023a; Raja et al., 2021), and worked as a team (Raja et al., 2021) were most desirable. These features support the idea that the factors valued by individuals with a rare disorder may not simply be experience and knowledge, but characteristics of person-centred clinicians.

The experience of stigmatisation and unhelpfulness is not uncommon across the CRPS and chronic pain literature (Bean et al., 2022; Beerthuizen et al., 2009). Many within the present study found that healthcare professionals were a source of stigma. A survey by Album and Westin (2008) found that chronic pain conditions such as Fibromyalgia ranked the lowest on the scale of medical prestige. The authors suggest the lack of technology advancements and invasive procedures were proposed as the cause for this lack of prestige. The perceived lack of prestige from healthcare professionals may account for the experiences of stigma for those with chronic pain (Bean et al., 2022). It should also be noted that working in a chronic pain setting can be emotionally challenging for healthcare professionals too. Clinicians are frequently exposed to negative emotions and detailings of trauma with limited training on how to deal with these encounters (Goubert et al., 2005). One study found that emotional exhaustion was reported by 21.6% of clinicians working within multidisciplinary pain clinics (Ashton-James et al., 2021). Experienced physicians have demonstrated an ability to downregulate their pain empathy response in neuroimaging studies (Decety et al., 2010); however, this protective emotional adaptation may not be present in all healthcare professionals. The apparent lack of empathy or compassion fatigue of healthcare professionals noted in the CRPS lived experience studies may also be due to clinician burnout. There is presently no research exploring the prevalence of clinician distress and burnout in CRPS. Understanding how clinicians can manage compassion fatigue and burnout in emotionally demanding interactions may help us understand how we can improve the healthcare journey for patients with CRPS.

The present study demonstrated that people living well with CRPS self-managed their symptoms in a variety of ways, with little to no consistency between people. Previous systematic reviews have shown inconsistent responses to CRPS interventions, drawing mixed results on interventions for pain (Ferraro et al., 2023; O'Connell et al., 2013) and rehabilitation (Smart et al., 2022). Within the present study, self-management was sought across categories of symptom relief, restoring function and psychological well-being; however, the adoption and maintenance of such strategies depended on efficacy, side effects and perceived movement towards their definition of living well. A recent systematic review of non-pharmacological treatments in upper limb CRPS found that most studies based treatments on pathomechanics and symptoms with minimal emphasis on person-centred treatment choice (Griffiths et al., 2023b). The present study emphasised the importance of person-centred treatment, whereby people continued strategies they perceived as helpful and stopped those that weren’t. Some authors suggest the variable response may be due to the lack of uniformity from the syndromic nature of CRPS, where varying disease mechanisms differ between people and, at times, change throughout the time course of the condition (Bruehl et al., 2016; Knudsen et al., 2023). Therefore, adopting a uniform, templated approach to management will produce mixed outcomes. This study has emphasised the importance of providing person-centred approaches, allowing the person living with CRPS to decide through trial and error, and experimentation. The specifics of self-management strategies may depend on personal needs and preferences.

Only one self-management strategy was consistent across all participants in this study. Managing 'the pace of life' was defined as prioritising a finite amount of energy to manage symptoms whilst maintaining a meaningful life. Many spoke about adapting their pace by accepting they need to live life at a slower speed, making considerations for their painful limb. 'Pacing' is a common strategy taught through education in CRPS treatments (Beales et al., 2023; Moore et al., 2022) and is frequently discussed as a coping strategy in lived experience studies (Beales et al., 2021; Johnston-Devin et al., 2021). 'Pacing' remains a recommended strategy across guidelines for CRPS (Guy et al., 2019; Harden et al., 2022); however, other studies have recognised 'pacing' may contribute to perpetuating avoidance (Hadzic et al., 2017). In these cases, the concept of 'pacing' is primarily a provided strategy from healthcare professionals. This study found people changed 'the pace of life' through experiential testing, rather than strict rules dictated by their healthcare professional. Recalibrating a new pace of life was a tool to offer control from CRPS-related symptoms and permitted people to allocate a finite level of energy, subsequently moving them closer to a life of purpose and meaning. Understanding the patient-led development of 'pacing' through experiential means may provide future patients with the flexibility to maintain symptom control whilst pursing their life values.

Rebuilding Purpose and Meaning With a New Identity

Accepting that CRPS would be a part of their future lives was a prerequisite to living well with CRPS for participants in the current study. In the literature pertaining to chronic pain, acceptance is defined as the willingness to experience pain without attempting to control it in order to experience life's values (Hayes et al., 2006). Within this study, the participants articulated an active shift from seeking symptom elimination to restoring meaning and purpose in their lives. Of note is that the participant characteristics demonstrated high CPAQ-2 scores, which supports the participants' narratives that living well and accepting chronic pain are connected. In CRPS literature, greater pain acceptance is associated with greater activity and improved mood (Cho et al., 2013), while in chronic pain, greater pain acceptance has been linked to less distress and disability while improving physical performance in chronic pain (Vowles & McCracken, 2008). The term acceptance and derivations of (accepting, accept) feature centrally within the CRPS lived experience literature (Beales et al., 2021; Johannesson et al., 2023; Johnston-Devin et al., 2021; Kwon & Kim, 2021; Rodham et al., 2012; Rodham et al., 2013). The description of accepting CRPS varies from coming to terms with the fact your body can do less (Johnston-Devin et al., 2021), to giving up the fight and resignation of life (Kwon & Kim, 2021) and accepting the fact there is no cure for chronic CRPS (Rodham et al., 2013). These descriptions differ somewhat from the Acceptance and Commitment

Therapy (ACT) model, which defines acceptance in domains of pain willingness and activity engagement (Hayes et al., 2006). Two other studies position definitions of acceptance similar to ACT, describing the desire to move forward (Rodham et al., 2012) whilst living life in line with values (Johannesson et al., 2023). Many of the authors conclude that acceptance appears necessary for coping and is concerned with living a normal life, but note acceptance is difficult to articulate. Whether pain acceptance is an innate characteristic or a learnt therapeutic process is difficult to determine. The present study confirms that living well with CRPS is connected with the one's willingness to experience pain in order to re-engage with activities of meaning.

A further finding in the present study was how individuals reallocated their energy spent 'living *against* CRPS' to restore their sense of self. At its core, living well with CRPS was the decision to live their lives by rebuilding purpose and meaning. For most, this included re-engaging with valued activities by not worrying about the form and simply engaging with the function. The concept of psychological flexibility, or one's persistence in living life in line with values in the presence of pain (Kashdan & Rottenberg, 2010), appears to be important for individuals to live well with CRPS. This concept of viewing one's "self as context," or viewing myself as more than a label, including who they are as a partner, parent, role in their work or community, or many other layers of their identity, shares strong parallels with ACT (Hayes et al., 2006; Vowles & McCracken, 2008). In the case of the current study, re-engaging with activities of meaning and purpose further supports their willingness to experience symptoms (accepting), if this simultaneously moved them closer to restoring their sense of self (activity engagement) (Vowles & McCracken, 2008). Although ACT has not been studied directly in CRPS, the intervention is common in the wider chronic pain research. ACT has demonstrated limited effectiveness for pain or distress but recent systematic reviews report large benefits for reducing disability in chronic pain populations (Williams et al., 2020). Overall, the important feature within this study was the decision for committed action and movement towards re-engaging with valued activities. Although this aligns with ACT, the premise remains understudied in CRPS and should be a target for future research.

This study deviated from previous chronic pain acceptance literature by describing acceptance as something compatible with hope. Traditionally, chronic pain research often sees seeking a cure as contradictory to pain acceptance (Clarke & Iphofen, 2007). In a study featuring women living with Fibromyalgia, acceptance was described as a process that "allows people to redirect their energy from finding a cure" (Lachapelle et al., 2008, p. 203). However, the present study demonstrated that people can still live well with CRPS and retain the hope that one day, their symptoms will resolve. Some participants mentioned future biomedical advancements, whilst others hoped it would improve with the persistence of self-management. I termed this ‘conditional acceptance.’ One differentiation may be those living well with CRPS had stopped actively seeking a cure. Importantly, this study found that people may retain hope as long as hope is not a barrier to them pursuing life in line with their values.

The concept of hope and optimism was prevalent in the participants' narrative. Hope has not been studied in CRPS, but hope and optimism are described in chronic pain literature (Shanahan et al., 2021). Some authors suggest that hope fosters resilience and problem-solving to find alternate routes, reducing the likelihood that one's goals are unattainable and thus focussing on the loss due to pain (Shanahan et al., 2021). Personality traits like optimism appear to be important resources in the adjustment of pain (Wright et al., 2011). This study demonstrated that people living well with CRPS were often more problem-solvers and active participants in their recovery rather than passive recipients of healthcare. Problem-solving has been described as a means of coping in previous lived experience literature. In an interview study of 17 people living with CRPS, ‘confronting problems’ through active problem-solving approaches, such as adapting self-care, doing online shopping, and making ready-made meals, was deemed a key feature in what the authors termed either being a ‘warrior’ or a ‘prisoner of war’ (Johnston-Devin et al., 2021). One feature of this trait may be an individual’s psychological flexibility, or one’s persistence to live life in line with values despite adversity (Kashdan & Rottenberg, 2010). It may be that people who live well are more psychologically flexible and can, therefore, remain optimistic and hopeful whilst pursuing life goals in the presence of pain.

The participants in this study described resilience as a feature that permitted them to rebuild their lives in the face of significant barriers. Resilience is defined as the positive adaptive processes someone applies when coping with adversity or change (Richardson, 2002). Within this study, many spoke about overcoming adversity, whether in the form of physical symptoms, stigmatisation, or loss of employment. Resilience was described but not investigated in depth in CRPS qualitative literature, often discussed in terms of ‘trying not to let it stop me,’ and ‘working around it’ (Griffiths et al., 2023a), ‘not giving in’ (Johnston-Devin et al., 2021), and ‘not yielding to CRPS’ (Raja et al., 2021). Resilience has only been explored in two studies with CRPS populations (Bodde et al., 2014; Wertli et al., 2023). In a population with amputation due to longstanding therapy-resistant CRPS type-I, high resilience was positively related to higher quality of life (Bodde et al., 2014). In a more recent study by Wertli et al. (2023), levels of resilience were correlated with higher levels of quality of life and lower levels of anxiety, depression and fatigue in people with CRPS type-I. Within the wider chronic pain literature, resilience correlates to improved physical functioning (Sheedy et al., 2017), positive coping (Karoly & Ruehlman, 2006), and decreased distress, and catastrophising (Ong et al., 2010). Resilience measures have predicted better outcomes following functional restoration programmes (France et al., 2020) and improved return to work for those with chronic pain (Wainwright et al., 2019). One proposed feature for resilience is the mitigation of pain catastrophising in fear avoidance (Sturgeon & Zautra, 2013). Responses to pain, notably catastrophising and negative affect, have been proposed to lead to pain-related fear and avoidance (Vlaeyen & Linton, 2000). A recent study found resilience was a pain-related protective resource when incorporated with fear avoidance in people with low back pain (Slepian et al., 2020). Additionally, Sheedy et al. (2017) found that engaging in valued life activities, caring for others, optimism, and physical activity fostered resilience and coping. Resilience includes not only the features of coping but also the wider personal attributes, transactional processes, and experiences throughout life (Karoly & Ruehlman, 2006). Resilient individuals tend to draw on positive problem-solving skills, be optimistic, manage setbacks well, and have a greater sense of purpose and meaning in their lives (Sturgeon & Zautra, 2013). These features have previously been discussed in a population living well with chronic pain (Lennox Thompson, 2015). Resilience therefore appears to be a determinant in those living well with CRPS. One implication of this may be exploring whether people can develop resilience or, rather, those living well were just born more resilient. Interventions could determine whether we can build resilience in people not living well, or conversely, whether our interventions for living well need to be modified to all people living with CRPS.

Implications for Clinical Practice

This research contributes to the CRPS literature by identifying the significant impact CRPS has on the lives of individuals and documents the processes people take to reach a point of living well with CRPS. These findings feature the voices of people living with the condition; therefore, clinicians and healthcare professionals can implement these themes to improve the quality of care for people starting their journey with CRPS.

Conventional clinical practice is dominated by deficit and disease-centric assessment and treatments. As discussed in the introduction, the presumption that relieving disease and pathology can improve one’s quality of life is a foundation of modern biomedicine. Therefore, much of the health research typically focusses on identifying risk factors, signs of pathology, and treatments to reduce distress and deficits, hoping to improve health and well-being. This research demonstrated the value of adopting a positive and strength-based focus to better inform the lives and healthcare processes for future individuals. At the primary level, this research confirmed that people can and do live well with long-term CRPS. Listening to and honouring the voices or those who remain absent in research has significant value in clinical practice. One implication may be the development of strength-based services, including the role of peer-support or consumer-led resources. Like the role GAPPA plays in supporting the IASP in developing research and clinical practice, including individuals who live well with CRPS may change the predominance of negatively focussed research and confronting and distressing information seen online.

Many studies have highlighted the impact chronic pain and CRPS have on one's sense of self (Antunovich et al., 2021; Bury, 1982; Johnston et al., 2015; Morley & Eccleston, 2004), but few have identified how the shifting identity process is achieved in individuals rebuilding their sense of self. The present study demonstrated that individuals accepting the disruption and loss of their former self provided them with an opportunity to rebuild a new life with a new identity closely aligned with their pre-CRPS values. These findings suggest that identity shifts are expected, and healthcare professionals should support people by guiding them towards identifying their values and restoring a coherent sense of self. This study found that demonstrating to individuals with CRPS that they may find a life of meaning and purpose through deconstructing their pre-CRPS life may relieve their anxieties and aid the transition from 'living *against* CRPS' to 'living well *with* CRPS'. Many of those living well described having to reach their lowest point before instigating the changes to lives. Thus, if clinicians see their patients at their lowest point, they could support them to make a perspective shift, which at times can be very traumatic, but a necessary step for those who are living well. Equally, this may provide people with the reassurance that living well is the product of a journey. Currently there are few resources or therapies available to clinicians to support identify shifts and this may be a valuable area for development.

In addition, this study highlighted that individuals made sense of their condition in diverse and unique ways. Recent studies have identified the need to 'make sense' of the condition (Beales et al., 2023; Grieve et al., 2016; Griffiths et al., 2023a; Moore et al., 2022), noting which information appears 'important' for people to know (Moore et al., 2022). In the current study found that people living well did not necessarily make sense through the ideals of healthcare professionals, rather if a coherent explanation permitted them to live a meaningful life it was retained. One consideration may be that healthcare professionals need to consider focussing less on didactic neuroscience education and more on supporting an individual to make sense in their own unique way. This may include accepting people and all their beliefs, avoiding changing and challenging them, but rather strengthening those beliefs which improve function and support people to live well.

The participants in this study demonstrated a wide and varying range of self-management strategies which supported them to live well with CRPS. The current best practice guidelines recommend developing psychological and physical coping strategies, improving function and reducing the burden of pain to restore a meaningful life (Goebel & Turner-Stokes, 2018; Harden et al., 2022). The present findings highlighted that people need to trial a range of strategies through experiential testing, determining their effectiveness within the context of their own life. This notion counters the idea of the clinician as the expert and focusses on viewing the patient as the expert in their own recovery trajectory. Therefore, professions such as occupational therapy, where treatments are transitioned out of the clinic and into their context, may be an important component of the therapeutic approaches for this population.

The findings of this research raise a number of important questions as to the role of the clinician. When and how do clinicians help a person move towards acceptance? A great deal of energy and health resources are used during the 'living *against* CRPS' phase by individuals trying to navigate the system, fight against the lack of supports, trial interventions that don't work, and seeking the right practitioner. Clinicians may need to determine where someone is on the spectrum of living against versus living well and tailor treatments to support them at different stages. Moreover, are the interventions we use to navigate acceptance in CRPS effective? Given the nuances and complexities of what acceptance means for people with CRPS, is ACT a fit-for-purpose resource for CRPS? These are questions which need to be addressed to better support clinical practice and process of acceptance. ACT contains ideas about self and identity, committed action towards values, which share parallels with this research. One solution may be the development of specialised ACT for CRPS resources.

These findings demonstrate the value of psychologically informed interdisciplinary treatment which commonly includes individualised sensemaking, supporting the trial of self-management strategies, acceptance, living life in life with values, reevaluating identity, focussing on resilience, hope and optimism. Within the New Zealand context, CRPS pain management programmes are often provided by physiotherapists and occupational therapists. Further implications may be the understanding of how equipped these healthcare professionals feel to navigate these complex psychological topics. Future policy and healthcare focus needs to consider the lack of funding provided for training and support for such models. If we are to support individuals to live well with CRPS and reduce the already stressed healthcare system, instilling these changes may contribute to improving the identified dissatisfaction for people living with CRPS in the community.

Study Limitations

While this study on living well with CRPS contributes novel findings towards the body of CRPS literature, the limitations should also be acknowledged. First, this study utilised social media, previous CRPS research, and word of mouth to purposively sample individuals who self-identify as living well with CRPS. This recruitment strategy may be a limitation for identifying people who live well but was a pragmatic decision given the characteristics of the participants. As discussed in Chapter One and Two, people living well with chronic pain typically do not seek healthcare. They are, therefore, less likely to be recruited through traditional methods. Additionally, according to our study and previous chronic pain research, people living well are less likely to adopt CRPS as a feature of their identity. Therefore, the chosen recruitment strategy may not fully capture a living well population. It is possible that there is a subset of the population who are naïve to healthcare services and live well in more diverse and different ways. As such, the generalisability of these findings may not be applicable across all of the living well cohort. Repeat studies may consider alternate methodologies to include greater numbers or purposively selecting those who are already in peer-support coaching roles for people with CRPS.

CRPS is by definition, a syndrome, thus the condition encapsulates multiple undifferentiated conditions under one umbrella. One argument to consider is that such diverse presentations may have differing pathways toward living well, dependent on these subgroups. This current study had a diverse sample of varying degrees of symptoms, body site, and duration. Whilst this is an important consideration, at present, clinical practice classifies all individuals with CRPS into the same syndromic category and rarely differentiates the management between them. Therefore, these findings are applicable to the current understanding and best management for CRPS; however, in the future, CRPS may be reclassified based on diagnostic advancement, and therefore, these findings may be less applicable.

Unlike quantitative research, qualitative research utilises the researcher as a tool in the findings of a study (Denzin & Lincoln, 2018). The chosen method of reflexive thematic analysis features my sensemaking as I aim to make sense of participants' narratives. This means these findings relate to my understanding of the data, as a look through the lens of a physiotherapist working within pain management services. Therefore, future analysis of the uncoded data will likely produce an alternate interpretation with differing themes. However, it should be noted this is an important distinction between 'Big Q" research and neopositivist research such as codebook thematic analysis (see Methodology section) (Braun & Clarke, 2021b). My interpretation of the data using my experience as an advanced clinician physiotherapist is a strength of this study. I demonstrated methodological rigour through the detailing of my choice of reflexive thematic analysis, including the ontological and epistemological foundations of the research, my positionality and the theoretical underpinnings I bring to this research.

The present sample was all European. This was likely an unintended consequence of recruitment through social media. Importantly, the lack of cultural diversity will have an impact on the findings. Previous authors have documented the limitations of Westernised Anglocentric models of healthcare and the apparent incompatibility of Māori and other cultural groups' perspectives of pain and healthcare (Durie, 1998). Within the New Zealand context, Te Tiriti o Waitangi (The Treaty of Waitangi) sets particular standards to support Māori to overcome the inequities in health and research in the postcolonial context. As such, future research should seek to include Māori and other cultural groups to add diversity and different perspectives on pain, CRPS and living well.

Directions for Future Research

This study raises several important questions for future CRPS research. Despite the advancements in understanding the pathophysiology, risk factors and treatment effectiveness, the inclusion of lived experience through qualitative studies remains significantly underrepresented. As discussed in Chapter Two, qualitative CRPS studies are gaining momentum, yet studies featuring those living well, remain very uncommon in chronic pain and non-existent in CRPS research. Given the limitations in treatment effectiveness and lack of a present-day 'cure' for CRPS, there should be a greater emphasis on how people can live well, cope, and self-manage with their current condition. We should be featuring the voices of those living with the condition and learning from their experience as they can be experts in the condition. Future research needs to consider the value that qualitative strength-based research brings to healthcare and clinical practice.

To further understand how people make sense of CRPS, future studies need to explore the sensemaking interventions we provide in healthcare settings. Of note, people living well with CRPS desired to understand their situations better, yet the traditional model of pain education appeared dissonant and lacked coherence. Future researchers need to consider how we can develop sensemaking interventions that are not didactic-style teaching. Is there an avenue for individualised, flexible thinking, driven by the person living with the condition? Such questions could be answered by the development of co-led research with both healthcare professionals and lived experience advisors to develop future educational resources.

The concepts of acceptance, redefining one's identity and sensemaking were emphasised through the themes of the present study. Exploring a treatment intervention combining these features would be of value to both researchers, clinicians and people living with CRPS. A model of care or treatment guidelines could be developed to better support individuals starting their journey with CRPS. Additionally, these treatment interventions could utilise a peer-support model or lived experience coaches to provide the shared understanding which is desired by people living with CRPS.

The concept of retaining hope whilst accepting one's situation appears counterintuitive to traditional models of pain acceptance. This study demonstrated that people can retain hope that there will be a cure for their condition whilst maintained a life they considered living well. Future research could therefore consider the role of hope in living with CRPS with the demonstrated understanding that these concepts can co-exist.

The qualitative findings of this study could be developed into a quantitative survey to reach a wider sample and test the generalisability of the findings. Despite the widely identified differences in presentation and experiences both within and between individuals with CRPS, there may be some features of living well that are ubiquitous at a population level. Such features may provide a starting point for researchers and healthcare professionals creating interventions to support people to live well.

Conclusion

This study has demonstrated that living well is possible and achievable for those living with long-term CRPS. It contributes to the body of CRPS literature by identifying the meaning of living well with CRPS as the restoration of one's sense of self by focussing on living alongside, in partnership with, their painful limb. This study is novel and offers new insights in a positive strength-based approach to CRPS management, detailing the journey from living *against* to living well *with* CRPS. Participants described their journey in terms of making sense, taking control, and rebuilding a purposeful life with a new identity. This study featured the voices of those living with CRPS who are often underrepresented or silent in the research. I hope the described living well strategies can be incorporated into healthcare and therapies to support all people with CRPS to live well with their condition.

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Glossary

Allied health	Healthcare professionals who are not medical, dental or nursing
Allodynia	Pain due to a stimulus which is not normally painful e.g. light touch
Atrophy	A decrease in organ size or wasting of tissue
Dystonia	Involuntary contraction of muscles resulting in abnormal posture of a limb
e-Delphi	A research method which uses a panel of experts
Hyperalgesia	An increased sensitivity to pain
Hyperesthesia	A painful syndrome characterised by abnormally painful response to stimulus
Karakia	A Māori prayer or speech used to invoke spirtual protection
Kaupapa	A Māori approach or value
Mana	A Māori supernatural force representing power, influence and status
Manaakitanga	The Māori word for hospitality and generosity
Māori	The indigenous people of New Zealand
Somatosensory cortex	The region of the brain representing light touch, proprioception, temperature and pain.
Sudomotor	The function of the autonmic nervous system that controls sweating
Sympathetic nervous system	A division of the autonomic nervous system that regulates involuntary physiological responses
Tikanga	Encorportating Māori culture, customs and practices
Trophic	Abnormalities of an area of pain including wasting of the skin, muscle, tissue, bone, hair, and nails
Vasomotor	The function of the autonomic nervous system that controls blood flow

Appendix A: Ethics Approval

TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Auckland University of Technology Ethics Committee (AUTEC)
Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

14 June 2022
Debbie Bean
Faculty of Health and Environmental Sciences

Dear Debbie

Re Ethics Application: **22/119 Living well with Complex Regional Pain Syndrome (CRPS): A reflexive thematic analysis**

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 14 June 2025.

Non-Standard Conditions of Approval

1. The interview exclusion criteria needs to include that current and former patients of the research team will be excluded.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.
8. AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)
The AUTEC Secretariat
Auckland University of Technology Ethics Committee
Cc: mcvicar.tim@gmail.com

Appendix B: Participant Information Sheet

Participant Information Sheet

Date Information Sheet Produced:

05/05/2022

Project Title

Living Well with Complex Regional Pain Syndrome

An Invitation

Kia ora, my name is Tim McVicar. I am researching the experiences of people who live well with Complex Regional Pain Syndrome (CRPS). I will be doing this research along with Dr Debbie Bean and Dr Bronwyn Thompson as a part of my Master of Health Science qualification at AUT.

We would like you to consider participating in our interview study if you meet the following criteria:

1. Were you diagnosed with CRPS more than 12 months ago?
2. Do you continue to report symptoms consistent with CRPS?
3. Are you over the age of 18?
4. Can you speak English well enough to participate in an interview study?
5. Do you feel you 'live well' with CRPS?

Our study consists of a brief questionnaire (20 minutes) with an interview (30-90 minutes) at a later date.

If you are interested, please check out the study website for more information: https://livingwellcrps.wordpress.com

What is the purpose of this research?

CRPS is a rare but debilitating pain condition. Despite this, some individuals find they are able to live well with their condition, whilst others experience greater challenges with distress and disability. There is limited research exploring the lived experience of CRPS and unfortunately no research, we are aware of, understanding those who live well despite their condition.

This research aims to fill the gap in the literature by asking the question, "how do people live well with complex regional pain syndrome?" The themes identified will be used to help people living with CRPS find their way toward a meaningful life, and to help healthcare professionals and family members support this.

The findings of this research may be used for academic publications and presentations.

How was I identified and why am I being invited to participate in this research?

We advertised through social media, CRPS charity groups and New Zealand's DHB tertiary pain services.

Some people may have been approached by participants who recently completed the study.

Do you feel you 'live well' with CRPS? How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

If you would like to participate you can access the questionnaire link at https://livingwellcrps.wordpress.com.

What will happen in this research?

Once you have read the information on the study website (https://livingwellcrps.wordpress.com) you will be asked to complete an online questionnaire. This questionnaire includes some eligibility criteria and three questionnaires about your pain intensity, CRPS severity and pain acceptance.

Following this, you will be asked if you want to participate in an interview. The interview can either be online or face-to-face at a location of your choice. The duration will be between 30 to 90 minutes and aims to explore your personal experience of living well with CRPS. The interviews will be recorded and transcribed later.

The data collected will only be used for the purposes of this research.

What are the discomforts and risks?

Talking about aspects of diagnosis, medical interventions and negative experiences of CRPS may be distressing for some. Negative experiences are not the aim of this study but those topics may arise as a part of your journey with CRPS.

How will these discomforts and risks be alleviated?

All interviews will be conducted in a sensitive manner by a researcher who is experienced in CRPS and is also an experienced physiotherapist.

AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call 921 9998.

let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health

What are the benefits?

The personal experiences and themes identified will be used to help people living with CRPS find their way toward a meaningful life, and to help healthcare professionals and whānau support this. You may find it personally meaningful to contribute to this goal.

The findings of this research may be used for academic publications and presentations.

This research project is part of a Master of Health Science qualification through AUT.

How will my privacy be protected?

All interviews will be recorded and transcribed at a later date. All data will be stored on an AUT secure database.

All interviews, transcription and questionnaires will be deidentified with a pseudonym. All identifiable features will be removed from the transcripts. Any presentations or reports from the research will not include information that could identify you but may include direct quotes from your interview.

Only the researchers on the team will analyse the information you provide in your interview.

What are the costs of participating in this research?

We ask for 20 minutes to complete the online questionnaire and 30 to 90 minutes for the interview.

What opportunity do I have to consider this invitation?

Interviews will open in May 2022 and will close in April 2023. Applications will close once 10 participants have completed the interview.

Will I receive feedback on the results of this research?

If you would like to receive a summary of the research findings, we will send this to you once the study is complete.

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, Debbie Bean, Debbie.Bean@aut.ac.nz.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, *ethics@aut.ac.nz* , (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Tim McVicar, mcvicar.tim@gmail.com

Project Supervisor Contact Details:

Dr Debbie Bean, Debbie.Bean@aut.ac.nz

Dr Bronwyn Thompson, Bronwyn.thompson@otago.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 14 June 2022, AUTEC Reference number 22/119.

Appendix C: Consent Forms

TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Consent Form

For use when interviews are involved.

Project title: ***Living Well with Complex Regional Pain Syndrome: A Reflexive Thematic Analysis***

Project Supervisor: ***Debbie Bean***

Researcher: ***Tim McVicar***

○ I have read and understood the information provided about this research project in the Information Sheet dated 05/05/2022

○ I have had an opportunity to ask questions and to have them answered.

○ I understand that notes will be taken during the interviews and that they will also be recorded and transcribed.

○ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

○ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

○ I agree to take part in this research.

○ I wish to receive a summary of the research findings (please tick one): Yes○ No○

Participant's signature: ....

Participant's name: ....

Participant's Contact Details (if appropriate):

……………………………………………………………………………………..

……………………………………………………………………………………..

……………………………………………………………………………………..

……………………………………………………………………………………..

Date:

Approved by the Auckland University of Technology Ethics Committee on 14 June 2022, AUTEC Reference number 22/119.

Note: The Participant should retain a copy of this form

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Oral Consent Protocol

For use when interviews are being conducted by videoconference.

Project title: ***Living Well with Complex Regional Pain Syndrome: A Reflexive Thematic Analysis***

Project Supervisor: ***Debbie Bean***

Researcher: ***Tim McVicar***

The participant joins the videoconference

○ Do you agree to my recording your consent to participate?

If they agree, then the record function will be activated and they will be asked the following:

○ Have you read and understood the information provided about this research project in the Information Sheet dated 03/04/2022

○ Do you have any questions about the research?

○ Do you understand that notes will be taken during the interviews and that the interview will also be recorded and transcribed?

○ Do you understand that taking part in this study is voluntary (your choice) and that you may withdraw from the study at any time without being disadvantaged in any way?

○ Do you understand that if you withdraw from the study then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used? However, once the findings have been produced, removal of your data may not be possible.

○ Do you agree to take part in this research?

○ Do you wish to receive a summary of the research findings? (please tick one): Yes○ No○

○ Do you want me to send you a copy of the audio recording for this consent? Yes○ No○

○ Please confirm you name and contact details

Participant's name: ……………………………………………………………………………………………

Participant's Contact Details (if appropriate):

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

I will now turn off the recording of the Consent and then will start a separate recording for the interview.

Approved by the Auckland University of Technology Ethics Committee on 14 June 2022, AUTEC Reference number 22/119.

Note: The Participant should retain a copy of this form

Appendix D: Māori Consultation support letter

13 May 2021

Auckland University of Technology Ethics Committee
Private Bag 92006
Auckland 1142

Tēnā koutou, AUTEC Secretariat,

Re: Māori Consultation for “Living Well with Complex Regional Pain Syndrome: A Reflexive Thematic Analysis”

Ngā mihi nui ki a koutou i tēnei ra, i tēnei wā

I met with Tim McVicar and Debbie Bean to provide Māori consultation on their proposed research project, Living Well with Complex Regional Pain Syndrome. It is appreciated that the qualitative design takes a mana-enhancing stance with the participants being acknowledged as experts in context of their personal narratives. Furthermore, encouraging is the strengths-based approach implicit within, and explicit of this project. It is therefore well-designed to collaborate, to engage with Māori.

We discussed the importance of acknowledging a Māori way of being that is being tikanga-based tikanga for example, practicing manaakitanga - to form relationships with participants, to listen to their stories, allow for comfort breaks, and to offer karakia. We discussed recruitment strategies and using the social media messaging to “front-up” and explain the kaupapa of the research (emphasizing the purpose of helping people).

He hōnore ki te tautoko i a Tim i roto i ana mahi. It is an honour to support Tim in his endeavours.

Tēnā rawa atu ki a koe

EMorunga

Eva Morunga (Ngā Puhi / Te Rarawa)
Kaiārahi, The University of Auckland Health Psychology Programme
Health Psychologist, Cancer Support, ADHB

Appendix E: A tool for evaluating thematic analysis (TA) manuscripts for publication

These questions are designed to be used either independently, or alongside our methodological writing on TA, and especially the current paper, if further clarification is needed.	
Adequate choice and explanation of methods and methodology	
1	Do the authors explain why they are using TA, even if only briefly?
2	Do the authors clearly specify and justify which *type* of TA they are using?
3	Is the use and justification of the specific type of TA consistent with the research questions or aims?
4	Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e. is there conceptual coherence)?
5	Is there a good 'fit' between the methods of data collection and the specific type of TA?
6	Is the specified type of TA consistently enacted throughout the paper?
7	Is there evidence of problematic assumptions about, and practices around, TA? These commonly include: • Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures • Combining philosophically and procedurally incompatible approaches to TA without any acknowledgement or explanation. • Confusing summaries of data topics with thematic patterns of shared meaning, underpinned by a core concept. • Assuming grounded theory concepts and procedures (e.g. saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification. • Assuming TA is essentialist or realist, or atheoretical. • Assuming TA is only a data reduction or descriptive approach and therefore must be supplemented with other methods and procedures to achieve other ends.
8	Are any supplementary procedures or methods justified, and necessary, or could the same results have been achieved simply by using TA more effectively?
9	Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?
10	Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)
11	Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did, rather than generic procedures?
12	Is there evidence of conceptual and procedural confusion? For example, reflexive TA (e.g. Braun and Clarke 2006) is the claimed approach but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).
13	Do the authors demonstrate full and coherent understanding of their claimed approach to TA?
A well-developed and justified analysis	
14	Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?
15	Are the reported themes topic summaries, rather than 'fully realised themes' – patterns of shared meaning underpinned by a central organising concept? • If so, are topic summaries appropriate to the purpose of the research? o If the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified? • Have the data collection questions been used as themes? • Would the manuscript benefit from further analysis being undertaken, with the reporting of fully realized themes? • Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA (e.g. coding reliability or codebook)?
16	Is non-thematic contextualising information presented as a theme? (e.g. the first 'theme' is a topic summary providing contextualising information, but the rest of the themes reported are fully realised themes). If so, would the manuscript benefit from this being presented as non-thematic contextualising information?
17	In applied research, do the reported themes have the potential to give rise to actionable outcomes?

18	Are there conceptual clashes and confusion in the paper? (e.g. claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours)
19	Is there evidence of weak or unconvincing analysis, such as: • Too many or two few themes? • Too many theme levels? • Confusion between codes and themes? • Mismatch between data extracts and analytic claims? • Too few or too many data extracts? • Overlap between themes?
20	Do authors make problematic statements about the lack of generalisability of their results, and or implicitly conceptualise generalisability as statistical probabilistic generalisability (see Smith 2017)?

Note. This tool has been retrieved from “One size fits all? What counts as quality practice in (reflexive) thematic analysis?” by V. Braun & V. Clarke, 2021, *Qualitative Research in Psychology, 18*(3), 328-352. https://doi.org/10.1080/14780887.2020.1769238

Appendix F: Interview schedule

Email prior to interview

Kia ora [insert participant],

Just confirming you are all set for our interview on [insert date and time]?

Please don't forget to complete the online questionnaire beforehand. This includes the consent form. *Let me if you have any questions about any of the info.*

Here are some of the themes we can discuss on Friday:
- *Your journey to diagnosis*
- *Making sense of CRPS*
- *Your journey to living well with CRPS*
- *What does living well with CRPS look like?*
- *Helpful strategies*
- *Turning points*
- *Milestones*
- *Advice to future patients*
- *Advice to healthcare professionals*

Looking forward to seeing you online then,

Tim

The interview

- Explain the study
- Confirm consent has been provided online for the interview
- Explain the use of a Dictaphone or audio recorder for online interviews and confirm that participants will be will not be named or identified
- Record and read the Oral Recording Protocol (see attached)

Introduction

"Thank you for agreeing to participate in the Living Well with CRPS study. We are conducting this research to explore the lives of people who self-identify as living well with their condition. We hope that the information you share could improve the lives of those living with the condition, as well as their whānau. We hope to share your experiences with healthcare providers and support workers to improve our healthcare systems understanding of living with CRPS.

We want to hear your thoughts, reflections and views on how you have lived well. We want you to guide us on your journey, the changes you made, and the turning points you discovered. If you don't feel comfortable talking at any point, please let me know and we can stop the interview."

"Before we start, [Record reading Oral Consent Protocol]."

"Do you have any questions before we start the interview?"

[Record on separate file for transcripts with pseudonym]

Indicative questions

[Participants are encouraged to lead and guide the direction of quesitoning. The interviewer will remain reflexive rather than pre-determined. Therefore the following questions are an indicative framework not a script.]

1. Tell me about your journey toward living well with CRPS

2. What have you found helpful?

*Prompts:
- What did you discover on your own?
- What did your therapy team support you with?
- What has your family helped with?
- What helped you cope?
- What strategies helped you move forward?

3. What have you found less helpful?

*Prompts:
- What strategies have you found unhelpful?
- What interactions were less helpful?
- How might you advise to make changes of these?

4. What were the turning points in your journey?

*Prompts:
- What milestones do you see?
- What changes did you make?
- What have you seen in others? Patients? Family? Community?

5. How have you made sense of living with CRPS

*Prompts:
- How did you make sense of the adjustments?
- How did you make sense of the diagnosis?
- What helped you make sense?
- Who helped you make sense?

6. Reflecting on your own experience, what advice would you give to other individuals?

*Prompts:
- What about family?
- What about healthcare providers?
- What about funders or government organisations?

7. How would you describe 'living well with CRPS'?

Extra cues:

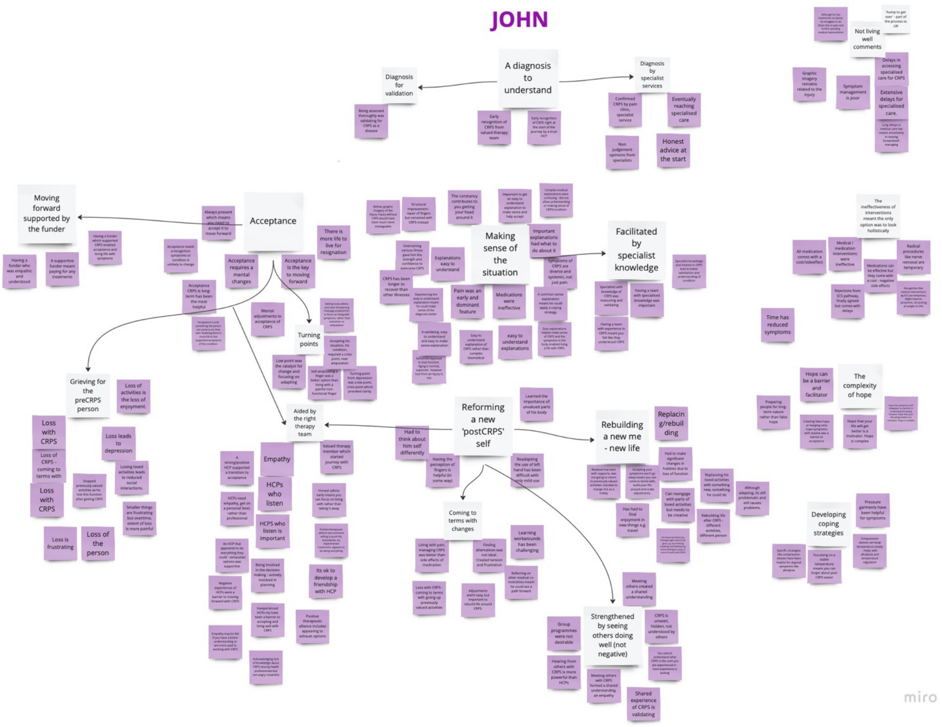
* How do/did cope/deal with that?
* Can you explain a bit more about that?
* How does that make you feel?
* Can you tell me a more about that?

Conclusion

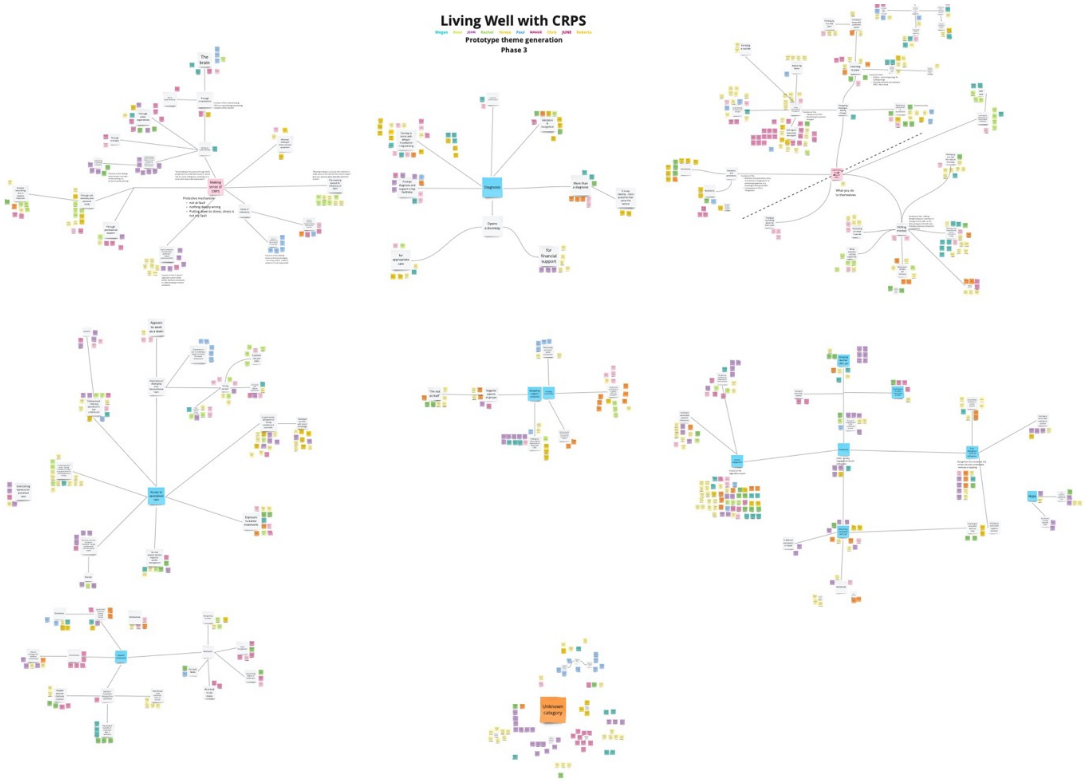
- Thank them for their time
- Re-request if they would like a copy of the final analysis. Confirm email address.

Appendix G: Sample of Coding for Thematic Analysis

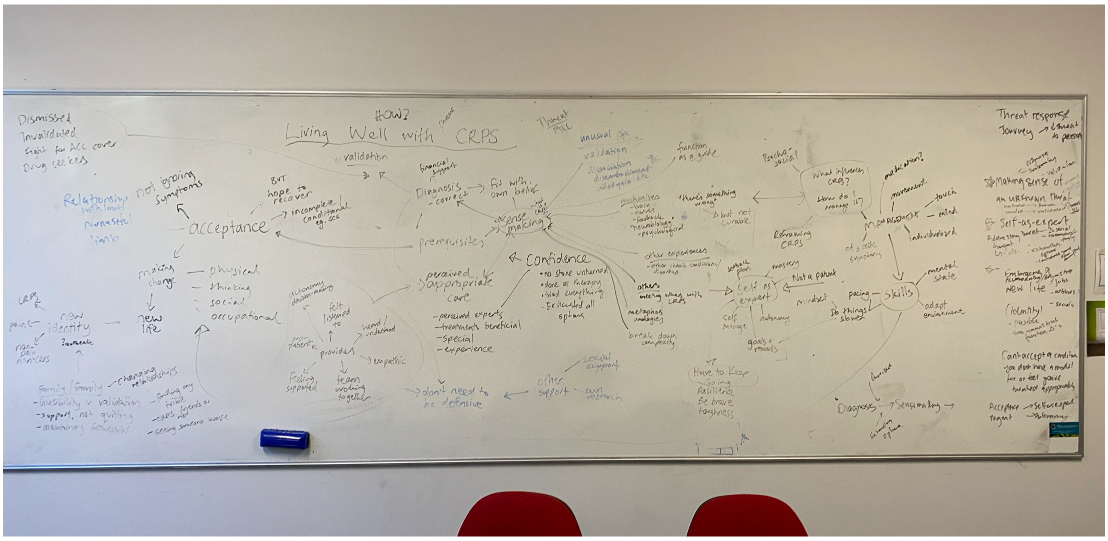
Initial coding (one participant)



Prototype themes (all participants)



Whiteboard theme generation



Final theme generation