

BATTLING COMPLEX REGIONAL PAIN SYNDROME (CRPS): A PHENOMENOLOGICAL STUDY

By

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A dissertation submitted in fulfilment of the requirements for the degree
of Doctor of Philosophy

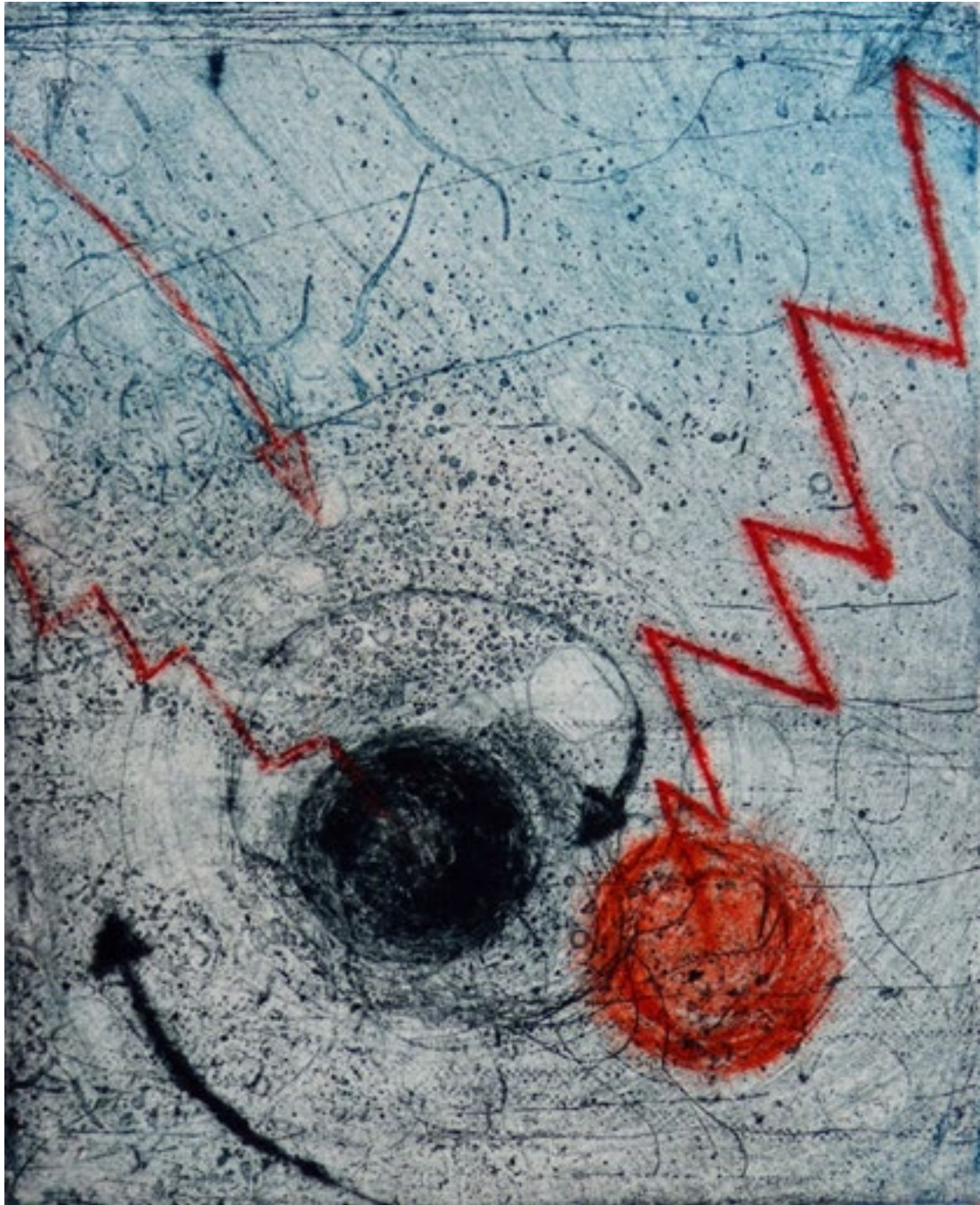
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'Shot'

'Shot' by Rosemary Eagle from the 'Language of Pain' series. This etching depicts a CRPS flare. (With permission from the artist).

ABSTRACT

Background: Pain is a subjective experience but Complex Regional Pain Syndrome (CRPS), which is reported to be the most intense pain ‘known to man’, has never been examined from the patients’ lived experience perspective. First observed in 1864, CRPS is a rare condition and remains largely unknown. It is thought that CRPS is activated by the dysfunction of multiple systems. People living with CRPS often take years before being diagnosed and referred to a specialist pain centre for treatment. Because there is no known cure, the goals of care are to reduce pain and improve function. CRPS can spread throughout the body and in extreme cases may require limb amputation. The consequences of living with CRPS can be debilitating. People with CRPS generally have a poorer quality of life and higher risk of suicide than people with other types of chronic pain.

Methods: This research utilised a phenomenological approach to investigate the phenomenon of living with CRPS. Seventeen people living with CRPS and four health professionals from 6 different countries were interviewed. Experiential material from internet blogs and a book containing patient stories were also included as data sources.

Findings: The overarching essence of the phenomenon was that people living with CRPS face a daily battle to live with this condition. The battle can be broken into 5 themes which describe different aspects of the battle. These sub-themes are: Dealing with an unknown enemy; Building an armoury against a moving target; Battles within the war; Developing battle plans with allies; and Warrior or prisoner of war.

Conclusion: This research suggests that people living with CRPS are facing a daily battle to live their lives. They face all the difficulties of living with a chronic pain condition alongside additional problems unique to CRPS. Support is not always forthcoming from the general community and some healthcare professionals are uninformed about the condition. The outcomes of this research will inform patients, carers, health care professionals and the wider community of previously unknown aspects of living with CRPS. The experience of people living with CRPS could be improved by increased community awareness and support and health professional education.

DECLARATION OF ORIGINALITY

The thesis is my own account of research undertaken by me; and

- the thesis has been wholly completed during candidature, except where the Committee has approved a transfer of enrolment from another higher degree by research; and
- where work has been done conjointly with other persons, my contribution is clearly stated, and the contribution of other persons is clearly acknowledged and recognised; and
- the thesis does not contain as its main content any work or material which is embodied in a thesis or dissertation previously submitted by me or any other person for a University degree or other similar qualification at this or other higher education institution, except where approval has previously been granted by the Committee.
- The thesis includes required acknowledgement of the Australian Government's Research Training Program Scholarship.

Signature:

6th June 2019

STATEMENT OF EDITORIAL ASSISTANCE

This thesis was edited by David Duncan who followed the Institute of Professional Editors guidelines for editors of a research thesis, which restrict services to copy-editing and proofreading.

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PAPERS AND PRESENTATIONS ARISING FROM THIS WORK

PRESENTATIONS

2013 – 2015 Various presentations on Complex Regional Pain Syndrome for Cluster for Health Improvement and FOSHEE HDR Research Days, Sippy Downs.

Johnston, C. (2014, 2016) 3 Minute Thesis Heats at FoSHEE Research Day and Finals USC Research Week, Sippy Downs, July.

Johnston, C. (2016) 3 Minute Thesis Heats FoSHEE Research Day 16 June, and Finals USC Research Week, Sippy Downs, 14 July.

Johnston, C. (2016) *Defining my methodology*. USC Research Week HDR Day, Sippy Downs, 11 July.

Johnston, C. (2017) *Disbelief and loss in the context of CRPS*. Faculty of Science Health, Education and Engineering HDR Day, Sippy Downs, 3 May.

Johnston, C. (2018) *Battling complex regional pain syndrome (CRPS): A phenomenological study*. USC Final Presentation, Sippy Downs, 23 April.

Johnston-Devin, C. & Oprescu, F. (2018) Managing the fire of chronic pain. Woodford Folk Festival, Woodford, 28 December.

Johnston-Devin, C. & Wallis, M. (2019) Insider Perspectives in hermeneutic phenomenology. International Institute for Qualitative Methodology Qualitative Methods Conference, Brisbane, 1-3 May.

PUBLICATIONS

Johnston, C.M., Oprescu, F.I., and Gray, M. (2015). Building the evidence for CRPS research from a lived experience perspective. *Scandinavian Journal of Pain*, 9: 30-37.

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POSTERS

Johnston, C., Oprescu, F., Gray, M. & Wallis, M. (2017) Living with CRPS: Patients in partnership. International Association for the Study of Pain CRPS Special Interest Group Conference, Cork, Ireland, 31 August – 1 September.

Johnston, C., Oprescu, F., Gray, M. & Wallis, M. (2018) Living with CRPS: A daily battle. Australian Pain Society and New Zealand Pain Society Conjoint Annual Scientific Meeting, Sydney, Australia, 8-11 April.

GLOSSARY OF TERMS

Allodynia	The experience of pain from a non-painful stimulation of the skin
CRPS	Complex Regional Pain Syndrome
ECG	Electrocardiogram
EP	Exercise Physiologist
GP	General Practitioner
HP	Health Practitioner
Hyperalgesia	An abnormally heightened sensitivity to pain
Hyperesthesia	An increase in the sensitivity of the senses (sight, sound, touch, smell)
IRC	International Research Consortium for CRPS
IASP	International Association for the Study of Pain
MRI	Magnetic Resonance Imaging
NeuRA	Neuroscience Research Australia
NHMRC	National Health and Medical Research Council
Nociception	The perception or sensation of pain
OT	Occupational Therapist
RPIS	Research Participant Information Sheet
RSD	Reflex Sympathetic Dystrophy
RSDSA	Reflex Sympathetic Dystrophy Syndrome Association
Sympatho-afferent coupling	Abnormal coupling between the sympathetic and afferent nervous system
TREND	Trauma Related Neuronal Dysfunction
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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KEY TO TRANSCRIPTS

There are many excerpts of interviews with participants presented in *italics* in this thesis. These excerpts are used to illustrate points made, and to give the reader an appreciation of the voice of the participants in their own words. In some cases, the transcript has been edited to make it more readable and to edit out irrelevant material. Spoken English can be very different to written English, and as some of the participants were heavily medicated and/or tired at the time of interview, some are difficult to follow due to repeated words and mid-sentence subject changes. In those cases where words have been omitted from the original transcript, it has been done to retain the context of the interview. Alterations have been made according to the following key:

...	An ellipsis indicates the speaker paused.
.....	A 5-dot ellipsis indicates the speaker paused for longer than 5 seconds.
(...)	An ellipsis in brackets indicates words have been taken out of the original transcript to either remove irrelevant words or remove sections of dialogue which make it more readable while retaining the meaning of the sentence or paragraph.
(words)	Words in normal text within round brackets indicates the researcher is inserting a definition or complete word to enable the reader to comprehend.
[words]	Words in normal text within square brackets indicates that identifying words have been removed.
{crying}	Words in normal text within curly brackets indicates an action of the participant.

FOREWARD

Hi, my name is Complex Regional Pain Syndrome... some friends who have known me for a very long time call me RSD or CRPS..... I'm an invisible inflammatory disease that attacks your sympathetic nervous system.

I am now velcroed to you for life. If you have CRPS you hope for remission but there is no cure.

I'm so sneaky--I don't show up in your blood work, in x-rays, MRIs can't detect me, basically there is no test to prove you have me. There are only tests to rule out other things.

Others around you can't see me or hear me, but YOUR body feels me.

I can attack you anywhere and anyway I please. And, I will. Constantly.

I can cause severe pain or, if I'm in a good mood, I can just cause you to ache all over.

Remember when you and energy ran around together and had fun?

I took energy from you and gave you exhaustion. Try to have fun now.

I can take good sleep from you and in its place, give you brain fog and lack of concentration.

I can make you want to sleep 24/7, and I can also cause insomnia.

I can make you tremble internally or make you feel cold or hot when everyone else feels normal.

I can cause one limb to change colour, look bruised, feel super sensitive randomly for seemingly no reason.

I can also give you swollen hands and feet, a swollen face and eyelids, swollen everything.

OH, and just because I started off in one part of your body, don't think I can't travel and affect other limbs or any other part of your body I so choose to torment. I can, and likely I will.

I can make you feel very anxious with panic attacks or very depressed. I can also cause other mental health problems. You know crazy mood swings? That's me. Crying for no reason? Angry for no reason? That's probably me too. It is hard to not feel hopeless when you have me beating your body up constantly.

I can make you scream out loud, anytime of day or night, anywhere you are because I can create pain that makes you sure someone just stabbed you with a knife. Making you look crazy is fun for me.

I can make your hair fall out, your nails become dry and brittle, cause acne, cause dry skin, the sky's the limit with me.

I can make you gain weight and no matter what you eat or how much you exercise, I can keep that weight on you. I can also make you lose weight. I don't discriminate.

Some of my other inflammatory disease friends often join me, giving you even more to deal with.

If you have something planned, or are looking forward to a great day, I can take that away from you. You didn't ask for me. I chose you for various reasons: That sports injury, needle stick, or that car accident, or maybe it was the surgery to correct a bone problem. Whatever the cause, I'm here to stay.

I hear you're going to see a doctor to try and get rid of me. That makes me laugh. Just try. You will have to go to many, many doctors until you find one who can even try to help you effectively. Most of them will make you feel like you are to blame, or worse, it is all in your head. I'll convince them that you are crazy because normal people know that you can't have all those symptoms all over your body and still walk around looking normal.

You will be put on the wrong medication for you, pain pills, sleeping pills, energy pills, told you are suffering from anxiety or depression, given anti-anxiety pills and antidepressants.

There are so many other ways I can make you sick and miserable, the list is endless - If your body is all of a sudden dealing with things that were never issues before ... yep that's probably me.

Shortness of breath or "air hunger?" Yep, probably me.

Bone density problems?

Can't regulate body temp and poor circulation?

Constant 'electric jolts'? Yep, probably me.

I told you the list was endless.

You may be given a TENs unit, get massaged, told if you just sleep and exercise properly I will go away.

You'll be told to think positively, you'll be poked, prodded, and MOST OF ALL, not taken seriously when you try to explain to the endless number of doctors you've seen, just how debilitating I am and how ill and exhausted you really feel. In all probability you will get a referral from these 'understanding' (clueless) doctors, to see a psychiatrist.

I will make you question your own sanity at times. I will make you contemplate unthinkable scenarios.

Your family, friends and co-workers will all listen to you until they just get tired of hearing about how I make you feel, and just how debilitating I can be.

Even after explaining to those you interact with regularly that I'm the most painful disease known to man, and there is no cure, they will say things like "I hope you have a speedy recovery". Those who don't know me well have no idea how cruel and unusual my punishment can be.

Some of them will say things like "Oh, you are just having a bad day" or "Well, remember, you can't do the things you used to do 20 YEARS ago", not hearing that you said 20 DAYS ago.

They'll also say things like, "if you just get up and move, get outside and do things, you'll feel better." They won't understand that I take away the 'gas' that powers your body and mind to ENABLE you to do those things.

Some will start talking behind your back, they'll call you a hypochondriac, while you slowly feel that you are losing your dignity trying to make them understand, especially if you are in the middle of a conversation with a "normal" person and can't remember what you were going to say next. You'll be told things like, "Oh, my sister had that, and she's fine on her medication" when you desperately want to explain that I don't impose myself upon everyone in the exact same way, and just because that sister is fine on the medication SHE'S taking, doesn't mean it will work for you.

They will not understand that having this disease impacts your body from the top of your head to the tip of your toes, and that every cell and every body system and organ can be affected.

The only place you will get the kind of support and understanding in dealing with me is with other people that have me. They are really the only ones who can truly understand.

AUTHOR UNKNOWN

This poem can be found on multiple websites and Facebook CRPS sites, usually with a message to share it. The author is unknown.

CHAPTER 1: INTRODUCTION

This chapter introduces the research project described in this thesis. It begins by providing the background and context of the research undertaken. Complex Regional Pain Syndrome (CRPS) is then explained, followed by justification for the study. The research question is outlined, and the researcher's pre-understandings and assumptions are made clear. Finally, an outline of the overall structure of the thesis is provided.

BACKGROUND AND CONTEXT

The motivation for this research came in May 2010 when I suffered a sporting injury. This resulted in an injury to my left thumb. The pain was excruciating, and I was certain I had something terribly wrong with me. The x-ray showed nothing but I almost fainted getting it taken. Over the course of the following three weeks, I saw a local physiotherapist and an occupational therapist (OT) who helped me to strap my thumb. On the suggestion of the OT, I went back to the general practitioner (GP) who ordered Magnetic Resonance Imaging (MRI) and wrote “? CRPS” on the request form. When I questioned what this meant I was told that it's an uncommon condition and to not worry about it. He gave me a script for Lyrica and for stronger pain killers. I went straight to Google and was shocked at the information I found on Complex Regional Pain Syndrome. Here was a girl with CRPS in a wheelchair after a minor knee injury and someone talking about amputation. No, I thought, I don't want to have that! I knew something was going on though as I couldn't get the pain under control and could not think clearly.

The MRI revealed a ruptured ligament and I was scheduled for surgery. In the meantime, I saw the OT again who made a splint for my thumb and I tried to carry on as normal but there was nothing normal about me. I couldn't sleep, couldn't think straight and kept bursting into tears. My entire hand was swollen and red and the pain was unbearable. I took to holding my hand away from me out of eyesight as that seemed to help the pain. When I saw the surgeon post-operatively, he and his specialist OT confirmed the diagnosis of Complex Regional Pain Syndrome. I asked how I was supposed to live with it and asked for help. As a single mother I needed to know how I was going to manage. The OT said that I most definitely had CRPS but that it is self-fulfilling and so to not think or talk about it and it will go away. My suspicions that this advice was inappropriate were confirmed when I started researching CRPS. Still, there was no information that I could find on how people live with the symptoms I had.

Chapter 1

Through my research I was learning about neuroplasticity and knew I had to stop abnormal pain pathways establishing themselves in my brain. I sat and touched my thumb as much as I could. This was difficult because even a light breeze hurt it when I walked outside. My entire hand would get hot, then cold, so I would put both hands on something hot, or cold, to normalise the sensation. At times I experienced my left hand changing colour to look like a salami. It was swollen, red, hairy and incredibly painful. I developed a tremor in my left hand and was unable to drive, unable to open a folder let alone draw blood at work. I had no sick leave left and struggled to lead my team but couldn't afford to not get paid. I couldn't do my own bra up. I was unable to brush my hair properly, pull up a zip, tie shoelaces or cut up vegetables or cook dinner. As a single mother, I struggled. My oldest son had a broken foot and was on crutches, while the two younger boys were not tall enough to hang washing on the line or takeover cooking dinner. My mother was away, and my partner was working overseas. I continued to see the local OT and she and my GP were doing their best to learn about CRPS, and I was referred to the persistent pain specialist at the hospital.

Luckily, that doctor had been made aware that I worked in an office above his at the hospital and when theatre was cancelled one afternoon, he saw me for an impromptu appointment. This was approximately four months after my injury. My official first appointment with him was seven months later. I left his office with a re-confirmed diagnosis, scripts for Tramadol, Amitriptyline and an increased dose of Lyrica. He also gave me a book to read and the number of a clinical psychologist. Despite immediately gaining 15 kilograms as a side effect of the medication, I remain convinced that this appointment saved me from developing major complications of my condition. Despite the importance of being seen by this pain specialist, it is pertinent to mention here that every single appointment with this doctor at the local public hospital was postponed at least once.

After joining an internet support group, I realised that my CRPS story was different to that of most other people with the condition. I was diagnosed quickly, received treatment almost immediately and had many advantages over others due to my being a registered nurse working in research at a hospital and having access to health professionals through work. I still had trouble navigating my way through my changed health circumstances and often wondered how other people coped. Forum members described their own difficulties living with CRPS and I realised there was a huge gap in knowledge about it. Like many forum members, I saw many health professionals over the next few years including: occupational therapists, physiotherapists, chiropractors, a clinical psychologist, a psychiatrist, a private pain

management specialist, three orthopaedic surgeons, a cardiologist, a neurologist, a rheumatologist, a naturopath, an osteopath, a kinesiologist, a massage therapist, and exercise physiologists. I have had x-rays, scans, nerve conduction studies, had an electrocardiogram (ECG) and halter monitor. I underwent a functional MRI and also had MRIs taken on my hand, full body and brain. I have been prescribed numerous medications including Mobilis, Endone, Tramadol, Amitriptyline, Lyrica, Norspan patches and Palexia which have caused side effects such as weight gain, constipation, blurred vision, nausea, dizziness, sleepiness, dry mouth, pitting oedema and difficulty concentrating. I've completed two pain management programs and a course on mindfulness. This is not unusual for a person diagnosed with CRPS.

After attending the first pain management program, I still had many unanswered questions and decided that I had to answer them myself. The program was run by health professionals who had no experience of chronic pain themselves. They had good intentions and were all nice people, but the program just was not good enough. They had no understanding of how hard it is to work when you can't think straight. They did not comprehend how you feel when you cannot dress nicely because due to weight gain, your clothes do not fit, and you can't drive to the shops to buy bigger ones because a) you can't drive anymore and b) you can't afford it after spending big amounts on medications and health professional visits. After discussions with other program attendees, I realised that few people know what life is really like when you live with a chronic pain condition, especially CRPS.

Today, eight years after developing CRPS, I am taking multiple medications and dealing with their side effects. I am under the care of a private pain specialist who heads a multidisciplinary team and I have excellent care. My thumb is fully functional, and my pain is under control. However, my body goes into fight or flight mode very easily and I must manage my condition carefully. Lack of sleep, too much stress, illness and travel can affect me adversely, but I have learnt to 'be kind to myself' and have realistic expectations of my body. Although I do get flares, my CRPS has not spread and I do not expect that it will.

A NOTE ON LANGUAGE

In the introduction and in some parts of the methods and findings sections of this thesis document the first person will be used. It is inappropriate to use the third person in qualitative research, a research tradition which values subjectivity, because "engagement with rather than detachment from the things to be known is sought in the interests of truth" (Sandelowski, 1986). Consequently, in the reporting of this research I used the first person, where

appropriate, to indicate my influence on the choice of topic, the methodology employed, the collection of data and the analysis. In addition, the term patient will be used throughout this thesis as it is “the most appropriate word for someone who is in contact with and using health care systems” (Wade & Halligan, 2003, p. 350).

WHAT IS COMPLEX REGIONAL PAIN SYNDROME?

Complex Regional Pain Syndrome (CRPS) is a rare, little known chronic pain condition which is difficult to diagnose, difficult to treat and is reputed to be the most painful condition known to man as measured by the McGill Pain scale (Bruehl, 2015; Tahmouh, 1981). It was first observed in the 16th century, and was fully described for the first time during the American Civil War in 1864 (Kocz, 2015). Despite this, it remains largely unknown amongst health care providers and even less so in the general population.

Throughout the years the condition has undergone various name changes including causalgia, shoulder-hand syndrome and reflex sympathetic disorder (RSD) (Bruehl, 2015), and although the name CRPS was coined in 1993 by the International Association for the Study of Pain (IASP), the outdated term RSD is still commonly used on the internet and by support groups, particularly in the United States of America (USA) which adds to the confusion surrounding this condition. Lack of agreement regarding diagnostic criteria and outcome measures has caused difficulties such as a lack of comparison studies and inability to empirically quantify rates of recovery or permanent disability (Bruehl, 2015; Grieve et al., 2017; Harden et al., 2017). The diagnostic criteria for CRPS has been refined over many years and was last updated by the IASP in 2012 (Bruehl, 2015; Kocz, 2015). Entitled the Budapest Criteria, clinical diagnosis is based on signs and symptoms such as those shown in Table 1.

Table 1. Budapest 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
- (Birklein & Dimova, 2017, p. 2)

Current understanding of the pathophysiological mechanisms involved in the initial development and the transition from acute to chronic CRPS remains unclear although current research leads to it being considered as activated by the dysfunction of multiple systems including an abnormal response to tissue injury, central and peripheral nociceptive sensitisation, altered nervous system function and sympatho-afferent coupling, abnormal vasculature changes, brain changes, autoimmune components, and an abnormal inflammatory response (Birklein & Dimova, 2017; Bruehl, 2015; Dirckx, Schreurs, de Mos, Stonks, & Huygen, 2015; Nader & Nair, 2015).

There are a variety of presentations; some patients report symptoms such as hyperalgesia, oedema, temperature and colour changes, allodynia, increased hair growth and abnormal sweating, but the common symptom is pain disproportionate to the precipitating event. It can take patients up to 30 months to be diagnosed and referred to a specialist pain centre for treatment, (Kocz, 2015). The consequences of having CRPS can be debilitating and people with CRPS generally have a poorer quality of life, and a higher risk of suicide than people with other chronic pain conditions (van Velzen et al., 2014).

Incidence

The incidence of CRPS is difficult to gauge and to date there have been few studies focussing on the epidemiological aspects of the disease. In most studies, women were found to be affected more frequently than men at a rate of three to four more times, (although a Korean study found the ratio to be 0.8:1 male to female) (Bruehl, 2015; Kocz, 2015). The average age of incidence ranges from 50 to 70 years of age, although children as young as 2 are known to have been diagnosed (Bruehl, 2015; Kocz, 2015). CRPS most often occurs after fractures and is more common in upper extremities, with approximately 60% in the arm and 40% in the leg (Harris, Bedini, & Etnier, 2016; Marinus et al., 2013). Although intravenous cannula insertion, injections, pregnancy, mild trauma, minor surgery, sprains, immobilisation and stroke or myocardial infarction are known causes, it can also occur spontaneously (Borchers & Gershwin, 2014; Bruehl, 2015; van der Veen, 2015).

The incidence of CRPS in Australia is unknown however Neuroscience Research Australia (NeuRA), an independent, not-for-profit research institute based in Sydney, estimates about 5000 Australians are newly diagnosed with CRPS every year, and in any given year, the prevalence is thought to be about 22,000 Australians suffering from CRPS (NeuRA, 2018). A study conducted in the Netherlands found the incidence to be 26.2 cases per 100,000 person-years while results from a US study found it to be less at 5.46 cases per 100,000 person-years (Bruehl, 2015; Kocz, 2015). It must be noted that both these studies based the CRPS diagnosis on the 1994 IASP diagnostic criteria, whereas the 2012 Budapest criteria is thought to halve that rate (Bruehl, 2015). Based on the assessment that less than 200,000 people in the US and less than 154,000 people in the European Union are affected by CRPS each year, the US Food and Drug Administration and the European Medicines Agency have granted the condition an orphan disease status (Bruehl, 2015; Grieve et al., 2017).

CRPS research

As is the case with other rare diseases, there was little financial incentive for the pharmaceutical industry to develop and market new treatments to treat or prevent CRPS until the Orphan Drug Act provided tax credits, funding and assistance for clinical research (FDA, 2018). Research consortiums such as Trauma Related Neuronal Dysfunction (TREND) in The Netherlands, and the International Research Consortium for CRPS (IRC) have been established to pool resources, addressing issues such as lack of funding and small research participant numbers for randomised clinical trials. The primary goal of TREND is researching methods to improve treatment and it is currently concentrating on trials, epidemiology, biomarkers and

genetics (TREND, 2018). The IRC is an organisation whose goal is to promote research directed at relieving the pain and disability of, facilitating prevention of, and ultimately finding a cure for CRPS (IRC, 2018). Thus, the majority of CRPS research has been, and remains quantitative.

Although research to date has largely concentrated on understanding the pathophysiology, diagnosing and treating CRPS, patients' voices have not gone unheard. CRPS patient representatives have been included in projects developing outcome measures (Grieve et al., 2017) and co-creating information leaflets (Rodham, Gavin, Coulson, & Watts, 2016) and patient conferences have been conducted with support groups including Burning Nights (UK) and Reflex Sympathetic Dystrophy Syndrome Association (RSDSA, USA). The inclusion of the patient in research endeavours has been at the discretion of the researcher. There are examples in the literature of lived experience being investigated but in each case, it is a specific aspect of lived experience that has been researched such as the exploration of participants lived experiences of CRPS to understand their specific information needs (Grieve, Adams, & McCabe, 2016). Despite these initiatives, there remains a lack of research looking purely at the lived experience of the condition for the purpose of understanding the patient experience.

JUSTIFICATION FOR THE STUDY

This study aimed to explore the phenomenon of chronic pain in the lifeworld of those living with Complex Regional Pain Syndrome. Qualitative research is an avenue to provide better understanding of CRPS (Butler, 2015; Harris et al., 2016; Johnston, Opreescu, & Gray, 2015) and a better understanding of lived experiences of pain creates the potential to improve clinical pain management by enhancing comprehension and empathy from clinicians (van Rysewyk, 2016). This knowledge in turn is anticipated to assist with early diagnosis, inform current treatment, and inform policy. It is also anticipated that empathy for the experience of living with CRPS will be increased as people in the general community gain an appreciation of the daily struggles patients often face.

Accounts of lived experience are valued by support groups such as Chronic Pain Australia who in January 2018, launched a Lived Experience Series which is a collection of patients' lived experience stories published monthly and sent to health professionals, the media, key health and social policy makers and parliamentarians to help increase understanding and de-stigmatisation of people living with chronic pain. "The series is designed to explain to people who don't live with chronic pain what life is like for those who do" (Graham, 2018). The IASP

advocates the use of patient voices in both research and education to achieve a humanistic, patient-centred approach to health care and to aid the understanding of the health care process and potential barriers to treatment effectiveness from the patients' perspective (Carr, Stinson, & Birnie, 2018). IASP make specific mention of narrative research and phenomenology to capture the voice of the patient and the 2017 IASP CRPS conference included a presentation by a person living with CRPS who is running a CRPS support group and charity in the UK. The 2018 conference for the Australian and New Zealand Pain Societies included qualitative presentations and acknowledged the value of qualitative research, advocating for more.

Pain advocacy group, Painaustralia, report that pain is the most common reason people seek medical help in Australia, yet it remains one of the most neglected and misunderstood areas of healthcare. Figures indicate that 1 in 5 people (including children and adolescents) in Australia live with chronic pain and this figure jumps to 1 in 3 for those over the age of 65. In 2007 in Australia, chronic pain was estimated to cost the economy more than \$34 billion per year, making it the 3rd most costly health problem and it is the 4th most prevalent reported medical problem (Painaustralia, 2018). Patients face long waiting times to access multidisciplinary pain services in public hospitals, frequently more than a year, resulting in deterioration in quality of life and reduction in ability to return to work. One explanation for this is that, as cited by Painaustralia (2018), the Faculty of Pain Medicine of the Australian and New Zealand College of Anaesthetists report that there are only 275 pain medicine specialists practising in Australia and they are unable to meet the needs of 20% of the population. Twice as many palliative care physicians are trained every year compared with pain specialists. There are only 12 paediatric pain specialists in the whole of Australia, and some jurisdictions have none at all and there are only six dedicated multidisciplinary paediatric pain services in Australia and only one of these in a regional centre (Painaustralia, 2018).

With high rates of incidence, damaging psychological effects and high monetary cost, it is important that chronic pain treatment and management is addressed appropriately. Chronic pain is known to impact people physically, mentally and socially and less than 10% of Australians with chronic non-cancer pain gain access to effective care, despite the fact that current knowledge would allow 80% to be treated effectively, if there was adequate access to pain services (Painaustralia, 2018). As it has not previously been undertaken, it is appropriate to conduct research within the CRPS population from a lived experience perspective because pain has been defined as a subjective, emotional experience, and CRPS is known to be the most intense pain. The main areas of significance for this study are the contribution to

knowledge in this area to inform government, health practitioners, people with CRPS and their support networks.

CHOICE OF METHODOLOGY

Phenomenology has been used to explore pain by philosophers such as Merleau-Ponty, Husserl and Heidegger as it refers to the understanding of human experience (Thacker & Moseley, 2012). Thacker and Moseley (2012) stated it “directly deals with the subjective areas of pain” (p. 411) and proposed first-person neuroscience – a combination of the subjective experience of the individual and data such as clinical observations which are collected from the third person physiological domain. Phenomenology has been used in CRPS research in the past with studies conducted by researchers such as Rodham, McCabe, and Blake (2009), who utilised interpretative phenomenological analysis when examining how an online message board was used by people living with CRPS, and when examining the experience of transitioning from a hospital rehabilitation program to home (2012).

This study used phenomenology as described by van Manen (1990) who states, “phenomenology attempts to explicate the meanings as we live them in our everyday existence” (p. 11). His approach to phenomenology was chosen due to it being relevant to those researching social science to transform lived experience descriptions into a word-based depiction of its essence (van Manen, 1990b). As CRPS treatment is palliative rather than curative and the goals of care are pain reduction and restoration or improvement of function (Birklein & Dimova, 2017; Harden et al., 2013; van Velzen et al., 2014), a study of the meaning of living with CRPS is required so that clinicians can better relate to their patients and in so doing, improve the quality of care they provide (van Rysewyk, 2016). According to Hansson, Elmqvist, Lindqvist, and Stening (2016) patients want their experience (or lifeworld) to be about belief and empathy, and they want to be accepted as people with pain, not just as pain patients. They state (p. 303) that “within our lifeworld, our body is a lived body” and “to live with pain is not only to live with the pain itself; it is about relating a body with pain to the world”. van Manen suggests the categories of lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality), “belong to the fundamental structure of the lifeworld” (1990, p.102), and offers these four existentials as guides to questioning, reflection and writing in the hermeneutic phenomenological research process.

THE RESEARCH QUESTION

Research aim

The aim of this research is: To understand the phenomenon of chronic pain in the lifeworld of people living with CRPS.

Research question

The research question is: What is chronic pain in the lifeworld of complex regional pain syndrome?

According to van Manen, phenomenological questions “ask for the meaning and significance of certain phenomena” (1997, p. 23) and in time, future research may consider phenomena such as pain or acceptance or frustration in CRPS. Considering the experience of living with CRPS has never been published, the research question in this study is necessarily broad.

EXPLICATION OF PRE-UNDERSTANDINGS AND ASSUMPTIONS

As previously stated, I was diagnosed with CRPS in May 2010 which provided the impetus for this research. The Background and Context section of this chapter provides an account of my experiences and through reading this, my pre-understandings become evident. Additionally, upon commencing this research, I had the following beliefs:

- a) I believe my story is very different to that of other patients;
- b) I am lucky that I was diagnosed quickly and received appropriate treatment quickly;
- c) Activity pacing is hard;
- d) My condition is not as bad as many other patients; and
- e) I can navigate the health system more easily than many other people because I am a registered nurse.

OUTLINE OF THE THESIS

Chapter 1 introduces the research. It outlines the background and context and explicates the researcher’s pre-understandings and assumptions. Justification of the research aim, and questions is also provided.

Chapter 2 describes the current literature surrounding the research topic. A narrative literature review was published as a component of this research and it is included in this

chapter. Further literature published after the included publication is included so that the thesis is current.

Chapter 3 discusses the chosen methodology and methods used in the research and includes a published article. It describes how the phenomenological approach was deemed the most appropriate for this research.

Chapter 4 provides the findings of this study and uses a battle analogy to describe what it is like to live with CRPS.

Chapter 5 is a discussion of the findings in relation to the literature and current pain theories. It also concludes the thesis and defines the strengths and limitations of this research. The significance of the findings and the implications for practice are also discussed in this final chapter.

CHAPTER 2: LITERATURE REVIEW

This chapter discusses current knowledge about living with complex regional pain syndrome. It commences with the publication “Building the evidence for CRPS research from a lived experience perspective” (Johnston et al., 2015), which was published in the Scandinavian Journal of Pain. This journal was selected because it publishes narrative reviews and is a well-known journal within the pain field.

Following the published article, literature published in 2015 onwards will be presented to provide the most current scholarly information about living with CRPS.

BUILDING THE EVIDENCE FOR CRPS RESEARCH FROM A LIVED EXPERIENCE PERSPECTIVE

This narrative review started when it was realised there was scant published research on the experience of living with CRPS. As there was no literature found which concentrated solely on living with CRPS, the search was broadened. The following databases were utilised: ProQuest, EBSCO, Informit, Scopus/Science Direct, Medline, CINAHL and Google Scholar. The search terms used were – complex regional pain syndrome, CRPS, reflex sympathetic dystrophy, RSD, chronic pain, fibromyalgia, rheumatoid arthritis, and lived experience. Inclusion criteria were qualitative research describing the lived experience of the condition under investigation and data collection through interviews, written in English and published between 1998 and 2015. Exclusion criteria were clinical trials where the primary focus was on treatment techniques or medication efficacy and research investigating the lived experience of chronic pain with a known origin such as back pain. A total of 12 articles were reviewed.

The themes found in this review were:

- Disbelief/invisibility of pain
- Loss
- Coping with a non-compliant/constant painful body
- Self-management
- Alleviating pain/treatment

One of the conclusions was that until we have research on the experience of living with CRPS, we will only have anecdotal evidence on which to base future management guidelines. The article is presented in the format in which it was published in the Scandinavian Journal of Pain, including the reference list. The original page numbers have been retained and the thesis page numbers added.



Topical review

Building the evidence for CRPS research from a lived experience perspective



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HIGHLIGHTS

- Literature on the lived experience of Complex Regional Pain Syndrome is non-existent.
- We review themes found in the lived experience of chronic pain.
- We propose a model of the lived experience of chronic pain.
- Discussion of CRPS research and future research.
- Patient experiences can inform the direction of National Pain Strategies.

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ABSTRACT

Background and aims: Pain is known to be a subjective experience yet the majority of pain related research does not address the lived experience of the condition. Difficult to diagnose, Complex Regional Pain Syndrome (CRPS) is often poorly managed. The aim of this paper was to identify and synthesise the currently available literature on experiences of living with chronic pain in order to understand where and how CRPS research may be best situated in the future.

Methods: A narrative review was performed and ProQuest, EBSCO, Informat, Scopus/Science Direct and Web of Science, Medline, CINAHL and Google Scholar were searched in order to identify the literature from 1998 until 2015. 301 papers were identified of which 197 described the lived experience of chronic pain conditions. 12 papers were examined closely to determine the experience of living with CRPS or a similar chronic pain condition that does not have a definite pain origin such as cancer or endometriosis.

Results: Known understandings of pain were identified and a model was developed depicting the lived experience of chronic pain starting with loss of the former healthy, pain free self and culminating in acceptance of the condition. Major themes identified were disbelief/invisibility of pain, loss, coping with a non-compliant/constant painful body, self-management and alleviating pain/treatment. The review also found that there is no peer-reviewed published literature on the lived experience of CRPS.

Conclusions: Little is known about the lived experience of CRPS. There appears to be a clear indication that research needs to be conducted into CRPS from a lived experience perspective in order to provide information to patients, the general public, health practitioners and policy makers of previously unknown characteristics of this condition which may improve health outcomes for this patient cohort.

It has been identified that patients and their families should be active participants in education of health practitioners and in providing information to inform the development of National Pain Strategies currently being devised throughout the world.

Implications: Research into the lived experience of chronic pain conditions, and CRPS in particular, can help to provide information to enhance understanding enabling national pain strategies and future treatment guidelines strategies to be devised appropriately.

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1. Introduction

Pain is most often defined as a subjective experience [1–4]. The recognition of pain as a subjective and individual experience led to the development of the McGill Pain Scale in the 1970s which is used widely throughout the world today [5,6]. Melzack, one of the developers of the McGill Pain Scale, stated “humans are fortunate to have language to express their pain so that it can be known to others and, we hope, can be diminished by our growing armamentarium of therapies.” (p. 202) [6].

Chronic pain is any pain which lasts longer than 3 months, can be caused by a variety of conditions and impacts on the person suffering it and their family in a number of ways [4,7–9]. Literature on the topic of the lived experience of chronic pain is common [e.g. 10–13]. Bendelow [14] stated that over the course of the 20th century, pain has been medicalised, explained and measured by objective signs. She asserted that accounts of pain focusing on lived experience encompass psychological, spiritual, interpersonal and financial aspects of chronic pain. Bendelow [14] has termed this ‘total pain’ (p. 59). Conditions causing chronic pain include musculoskeletal problems such as back pain, cancer, arthritis-rheumatoid and osteo-arthritis, stroke, amputation, migraine/headaches, fibromyalgia, post herpetic neuralgia, and Complex Regional Pain Syndrome (CRPS).

A CRPS pain flare is the most intense pain known to man, scoring higher than childbirth or amputation on the McGill pain scale [15]. Despite this, the subjective experience of CRPS has not been investigated. The research instead has been from a medical perspective primarily associated with diagnosis and treatment. It is proposed that it seems appropriate that some of the research into living with complex regional pain syndrome should be conducted from a lived experience perspective.

2. Background

Lived experience research is the study of human experience and how people live through these experiences, making sense of them [16]. In this instance, it would involve asking the person with CRPS

to describe their experience and explain what it feels like to live with their pain. Understanding the lived experience of the person assists practitioners to balance the self-care methods patients develop alongside the prescribed treatment for their recovery and allows the health practitioner to become aware of healing activities that they had not previously considered [17]. Becoming aware of the lived experience of the person with CRPS would similarly assist health practitioners in informing treatment and improving health outcomes for the CRPS patient cohort because decision making by balancing different types of evidence is necessary to ensure the best quality of treatment [18].

2.1. CRPS

Complex regional pain syndrome is a little understood chronic pain condition with a variety of symptoms which presents differently in each patient [19–24]. Excruciating pain that is disproportionate to the original trauma or injury is the major characteristic shared by people who suffer from this condition [19–24]. Data on the incidence of CRPS are scarce however studies from USA and the Netherlands indicate the incidence as approximately $20/10^5$ – $20.57/10^5$ [19]. These results vary partly due to the historical lack of standardised criteria for diagnosing the condition which has hindered the research into causes and effective treatment of CRPS [19,22,24]. The lack of standardised diagnostic criteria for CRPS have been criticised in the literature but the IASP Committee for the Classification of Chronic Pain has accepted the Budapest criteria which is being used more widely throughout the world for clinical and research diagnosis [19–22,24–26].

CRPS most often occurs following trauma [19–22,26]. It may be major such as a ruptured ligament, fracture, or nerve damage; very minor, such as a splinter or intravenous needle insertion; or in approximately 10–25% of patients, there is no precipitating injury [19–21,23,26,27]. CRPS occurs most frequently in the extremities and while clinical features vary between patients, sufferers of the condition report allodynia, hyperesthesia, oedema, motor impairment, trophic changes and increasing dysfunction to the affected limb [19,22,26]. Patients presenting after prolonged time in a cast

or splint often report many of the diagnostic signs of CRPS such as vasomotor and trophic changes but do not report continuing pain disproportionate to the inciting event [22]. Many patients report spreading of the condition causing enlargement of the original affected area and myofascial pain syndrome is evident in the supporting joint of most patients [22,24]. Some sufferers also report spreading to distant sites not adjacent to the original site of injury, and spreading to the opposite limb [24]. Many patients present with motor-neglect like signs through a protective nonuse of the limb due to pain or fear of pain, and report a sense of disconnection to the affected body part [28,29].

Questions remain as to whether CRPS I (previously known as reflex sympathetic dystrophy where there is no nerve involvement) and CRPS II (previously known as causalgia where the pain is related to a nerve injury) should be included under the same designation [19]. For the purposes of this review, they will be combined under CRPS.

The aim of this paper is to identify and synthesise the currently available literature on experiences of living with chronic pain in order to understand where and how CRPS research may be best situated in the future.

3. Methods

Narrative review was deemed the most appropriate approach to the literature review as literature specific to the topic was not found; and a narrative review helps to present a broad perspective on a topic [30]. The decision was made to contextualise the issue using broader literature, concentrating on the known understandings of chronic pain and discovering where the research on the lived experience of chronic pain conditions fits into what is already known. Manual thematic analysis was performed and 3rd party verification confirmed the themes found.

3.1. Databases used

The databases used to find articles included ProQuest, EBSCO, Informit, Scopus/Science Direct and Web of Science, Medline, CINAHAL and a Google Scholar search was in an attempt to understand the quality of life for a person living with CRPS. Key words used were 'complex regional pain syndrome', 'CRPS', 'reflex sympathetic dystrophy', 'RSD', 'chronic pain', 'fibromyalgia', 'rheumatoid arthritis', and 'lived experience' and the date was set from 1998 until 2015. The university librarian was also involved in order to cross check the search terms and results.

3.2. Inclusion criteria

Criteria for inclusion of the additional articles were:

1. The research must be qualitative.
2. The article must describe the lived experience of the condition under examination.
3. The method used to collect data must be interviews.
4. The participants must have either CRPS or a similar condition such as fibromyalgia or rheumatoid arthritis; or chronic pain.
5. The research must be reported in the English language.
6. The article must be written after 1998.

3.3. Exclusion criteria

Exclusion criteria were:

1. Clinical trials where the primary focus is on treatment techniques or medication efficacy, and where the lived experience

is collected more as secondary information or as adverse events during treatment.

2. Research about lived experience of chronic pain conditions with a definite origin such as endometriosis, cancer or back pain.

3.4. Literature search

Qualitative methods are appropriate when seeking to investigate the subjective lived experience; and the process of generating descriptions generally involves conducting interviews with people experiencing the phenomenon under review [10,31–33]. For the purpose of the review research such as clinical trials, where the primary focus is on treatment techniques or medication efficacy; and the lived experience is collected more as secondary information or as adverse events during treatment, was not included. A literature search looking at pain in general was conducted. Articles were considered if they concentrated on living with chronic pain in order to determine what is already known about chronic pain.

Additional articles were then sourced to determine what is known about the lived experience of chronic pain.

3.5. Results prism diagram

Table 1 is the results prism diagram. It must be noted that only one of the four articles found under the CRPS term was actually about CRPS and it examined the lived experience of patients returning home after participating in a hospital rehabilitation programme rather than the experience of living with CRPS [34]. This indicates a gap in the literature. The review of chronic pain literature yielded 301 papers. Specifically, 197 papers were found using chronic pain and lived experience as search terms. Articles examining back pain or cancer pain were excluded and then duplicates were removed. Papers were discarded if the title obviously did not fit the criteria. Abstracts were then examined and the full article was considered if the abstract met the criteria. Bibliographies were used to identify any studies not previously considered which informed the chronic pain literature but did not increase the number of articles describing lived experience that were considered. Following exclusions and duplicates, 12 papers remained which met the criteria. See Appendix A for included studies.

4. Results

Chronic pain is a subjective experience which is difficult to explain and is amongst the least understood phenomena in medicine [12]. Each person experiences pain in different ways and people are affected both physically and emotionally [4,6,10]. It was found that there are many similar themes in the body of literature on lived experience and chronic pain. These themes have been used in the development of the following model (Fig. 1) which depicts the inter-relatedness of these themes.

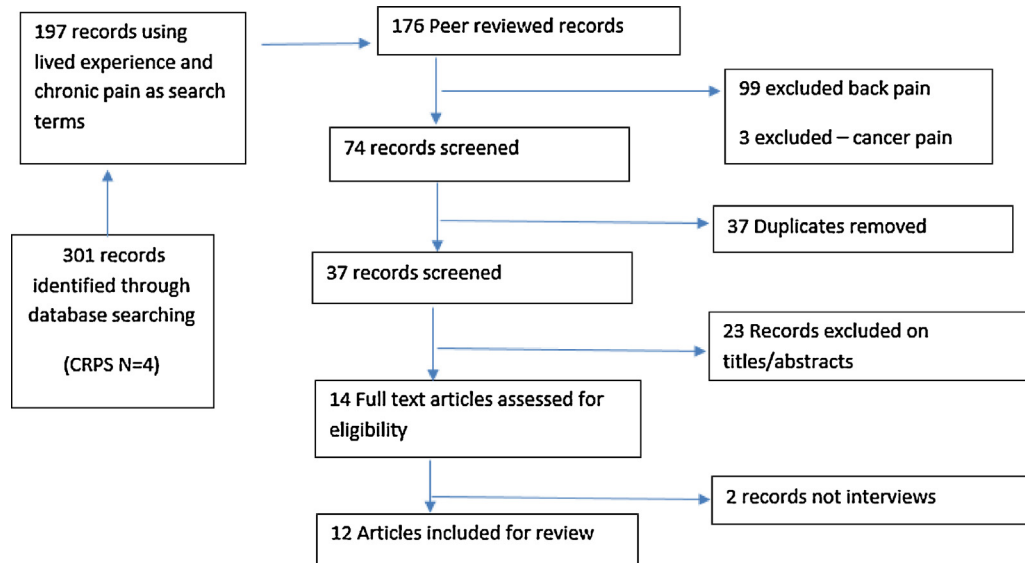
This model depicts themes emerging from the data on living and dealing with constant pain – the disbelief other people have of the symptoms, loss of the former healthy body, job, friends, lifestyle, the non-compliant, constantly painful body, self-management, treatment and alleviating pain [4,10,12,13,35].

These concepts will now be described in more detail.

4.1. Disbelief/invisibility of pain

Many authors reported the impact on individuals with chronic pain being disbelieved by others, including not only friends and family members but health care professionals also often trying to justify their symptoms which are invisible to others [4,27,36,37]. Key concepts emerging from this data were: stigma, isolation, and

Table 1
Results prism diagram.



emotional distress which were found to lead to depression, constant searching for symptom legitimisation and a breakdown of the relationship with health professionals. The theme of isolation was named by Rodham, Boxell, McCabe, Cockburn, & Waller [38] “It helped me realise it was not all in my head”. Those participants reportedly found relief in the fact that their symptoms were believed and meeting people with the same condition often validated their experiences.

Patients contradictorily describe not disclosing their pain to family members or carers so as to not upset or burden them along with disclosing their pain and not being believed [10,37]. This concept was first described by Parse [39] as ‘revealing–concealing’. Using the Australian word “bludgers”, Richardson [40] identified a term used to describe co-workers when they doubted the credibility of the so called ‘invisible’ pain experienced by the person with chronic widespread pain. Participants in this study strived to be seen as credible, hard workers as did participants in studies on fibromyalgia conducted by Juuso et al. [41]; and Paulson et al. [42]. Anecdotally, people with CRPS have written on internet forums about experiencing the disbelief others have of their pain (see <http://www.crps247.com/my-story.html> as an example) [43].

4.2. Loss

Results from studies of the lived experience of fibromyalgia indicate that loss is an important theme. Participants in studies by Söderberg et al. [44] and Juuso et al. [27] described a loss of credibility because of the disbelief by friends, family and health professionals in relationship with their illness. Individuals must walk the line between downplaying symptoms and risking not being taken seriously [40] compared to complaining too much and undermining their own authenticity [45]. Being given a clear diagnosis assists patients to demonstrate credibility. Patients often greet a diagnosis with relief, a validation of the difficult to describe, invisible illness [4,13,46].

The 14 women in the study conducted by Juuso et al. [41] 9 women in the study by Juuso et al. [27] and 15 men in the study by Paulson et al. [42] were met by society (including family, friends, and co-workers) with disbelief and were not taken seriously. As a consequence, these people with fibromyalgia struggled to cope with every day activities and felt their credibility was in question. Women reported that they did not accept pain but had learned to live with it, pursuing everyday day life as best as they could under their new life conditions [27,41]. Men acquired self-acceptance and



Fig. 1. Dealing with chronic pain. Where does CRPS fit?

found peace of mind once their symptoms were officially acknowledged by health and social security services and they were granted a disability pension [42].

4.3. Coping with a non-compliant/constant painful body

Many authors describe creative ways by which sufferers deal with, or live with constant pain [12,22,37,41]. While distraction techniques such as TV, alcohol, cigarettes, daydreaming, mindfulness, meditation and praying are commonly reported, pacing, planning future activities and structured daily routines are also advocated as helpful techniques [10,13,36,44,46]. These authors found that coping mechanisms also included an awareness of the symptom pattern, listening to one's body and gaining information from various sources such as health professionals, internet, and books, other patients and support groups. After diagnosis, finding acceptance and meaning in the illness is also advocated in the literature [37,42,46]. This re-evaluation of life can lead to a positive appraisal for some, but for others, it leads to a notion of being in despair and is too difficult to overcome [46].

Participants in the study conducted by Robinson et al. [13] described unpredictability in their day-to-day experiences. Utilising a moral discourse, participants conducted themselves in a manner actively trying to manage their pain and engage in activities. They wanted to be regarded as honest and doing their best to cope with pain rather than be seen as malingering or trying to get out of work for the day. In some instances they wished to conceal their pain from their friends and families in order to be considered as they were prior to their chronic pain condition.

Rodham et al. [38] describe this re-evaluation of life as battling for control and states that most participants in their rehabilitation programme reported that completion of the programme helped them to deal with their lack of independence. A few patients though, contrastingly reported they were handing over responsibility for their condition to others thus moving away from the rehabilitation programme goal of self-management [38].

4.4. Self-management

Published literature [34,35] supports the idea that self-management, supportive networks and active participation lead to better health outcomes for many people with chronic illnesses but fails to inform the reader how this can be achieved [47,48]. Self-management coupled with patient coaching interventions are often described and the International Association for the Study of Pain reports that training for people in pain and health care professionals in self-management strategies is needed [35,49].

Loeser and Cahana [8] advocated that multidisciplinary pain centres using a bio-psycho-social model are the optimum approach for chronic pain patients. They agree with Jordan et al. [48] and Kawi [35] that self-management and restoration of wellness behaviours must be achieved and state that health education plays an important role in achieving these goals.

Studies conducted by Rodham et al. [38] and; Rodham et al. [34] involved those discharged from a hospital rehabilitation programme and asked specifically about the lived experience of the transition from hospital to home. Rodham et al. [34] also describes advice patients would give to other patients with one recommending "sleep while you can" (p. 38). This was interpreted by the researchers as an inappropriate strategy. They stated (p. 38) "Although this approach worked for her, (it) was completely counter to recommendations from the rehabilitation programme". In the context of self-management and the individual taking control of their own health, there is an overtone of health practitioner control and judgement evident in this statement.

4.5. Alleviating pain/treatment

Robinson et al. [13] found that the healthcare experiences of participants were largely negative stating that their participants did not "use a biomedical discourse in the accepted manner . . . respecting the power and scientific knowledge of medicine and accepting the patient role" (p. 96). Some patients feel they have to describe pain using medical vocabulary [11] and this presents difficulties to those with little medical knowledge. Notwithstanding, most of the patients in the study by Clarke et al. [11] preferred to use descriptive language rather than numerical values to describe their pain. Interestingly however, the 7 Chinese participants in the study by Clarke found it relatively easy quantifying their pain finding verbal descriptions difficult as English is their second language.

Chronic pain patients are caught between the goals of medicine and those of business [8]. As drug and device manufacturers gain little from these patients, Loeser and Cahana [8] believe that the pursuit of an effective treatment does not recognise that chronic pain patients need more than physical symptom relief to return to a normal lifestyle and posit that repeated episodes of intervention (such as tests and pharmacologic treatments) have the potential to cause more harm than good. Medication is described in the literature as helping to alleviate the pain but as with all such treatments, unwanted side effects must be considered and perhaps is the reason that many people living with chronic pain turn to alternative treatments [10,25,44].

Alternative treatments may include kinesiology, meditation, massage therapy, homoeopathy and naturopathy. According to Boorsook [50] all treatments, including these alternative therapies, should be evaluated in clinical trials in order to ensure that patients are exposed only to treatments or practices which show benefit.

4.6. Proposed model

The second model (Fig. 2) was devised by extracting themes from the 12 articles specifically on lived experience and depicts the inter-relatedness that loss, coping with pain, being informed, and public, professional and self-acceptance have on the lives of chronic pain sufferers. It demonstrates where the known understandings of pain (identified in Fig. 1) fit into a model of lived experience of sufferers. In order to find acceptance in dealing with the challenges of chronic pain, people must strive to become informed. The literature points to this stemming from a background of loss of the former non-painful body and pain free way of life and a desire to live life as best as possible. This is achieved by education, health care provision or regaining some control and self-management.

5. Discussion

Borchers et al. [19] assert that CRPS clinical trials have reported changes in pain intensity as the most common outcome measure although the performance of activities of daily living and handicaps such as role fulfilment and limits in social functioning are becoming increasingly recognised. While the lack of effectiveness of current treatment strategies (both medical and alternate) is widely reported, cognitive behavioural therapy, graded motor imagery and gradual exercise leading programmes are often described in current literature as appropriate treatments, although randomised controlled trials supporting it are unreported [19–22,24,26].

O'Connell et al. [26] state that "there is a critical lack of high quality evidence for the effectiveness of most therapies for CRPS" (p. 2) and therefore believe there is difficulty in recommending which therapy should be offered. The formulation of evidence-based approaches to CRPS will remain problematic until larger scale trials are undertaken however lower level evidence and

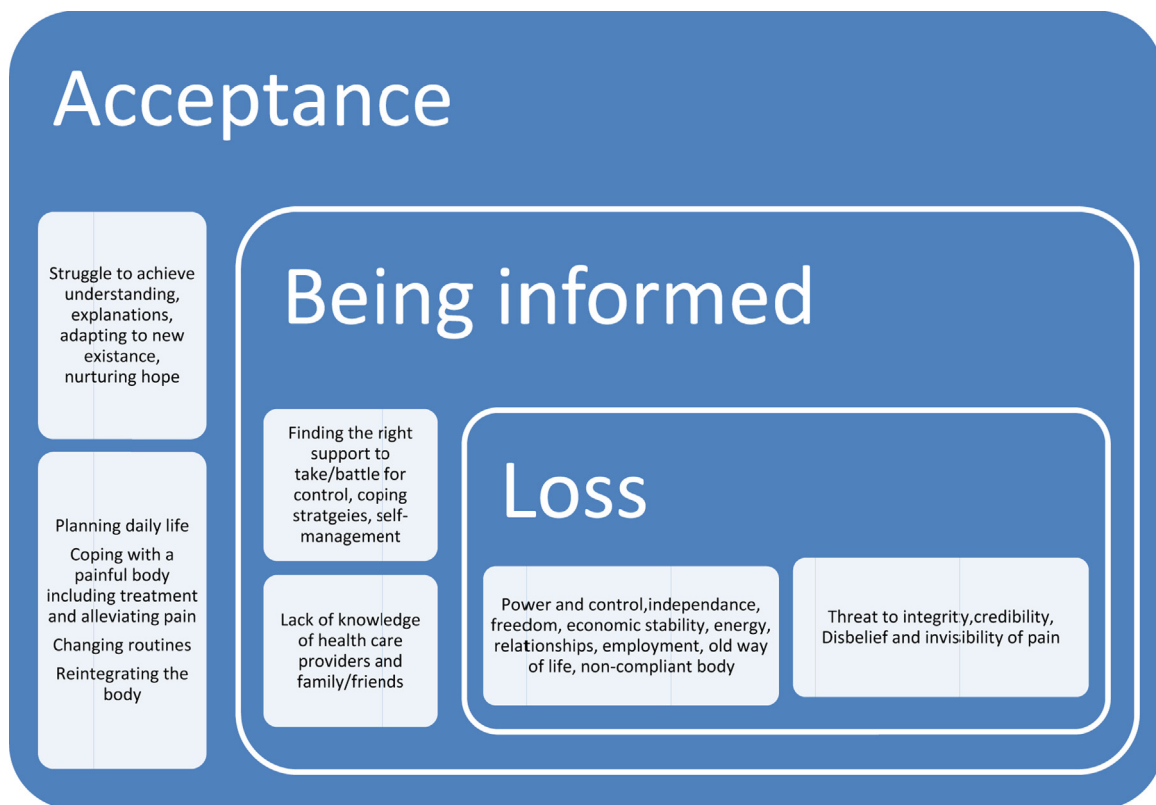


Fig. 2. Proposed model of lived experience of chronic pain.

knowledge from empirical clinical experience suggests that an interdisciplinary approach to functional restoration is the most cost-effective, pragmatic therapeutic approach [22,26]. Functional restoration involves the normalisation of activity through physical, medical, pharmaceutical and psychological approaches [22].

The ineffectiveness of many treatments might be related to the complex, multifactor pathogenesis and pathophysiology of CRPS and the fact the epidemiology is not yet well known [20,22]. The belief that not all disease mechanisms are equally prominent in all patients, and that the presentation often changes over time might explain why not one single therapeutic modality is successful in all patients although it is recognised that finding a common relevant factor in all CRPS patients would be difficult [20,22]. Recent literature reports that due to the poor understanding of the CRPS disease process and the delay in diagnosis of up to 50% of patients, patients may experience diverse treatment approaches, inappropriate treatment and poorly defined outcome measures [19–21,24,26].

Another factor to be considered in a discussion on CRPS is the majority of patient cohorts described in the literature consist of the most chronic and severe patients from tertiary pain clinics which does little to provide information on the overall outcome measure of CRPS [19,20]. Outcome measures are often poorly defined and debate remains over a definition of recovery from CRPS; it is suggested that this poses problems with diagnosis when patients lose their initial symptoms but are left with persisting pain [21,26]. The lack of standardised diagnostic criteria for CRPS have been criticised in the literature but the IASP Committee for the Classification of Chronic Pain has accepted the Budapest criteria for clinical and research diagnosis [19–22,24,25]. Treatment guidelines have been established and Harden et al. [22] have published a guide to pharmacotherapy and algorithms guiding overall treatment, psychological intervention.

There is important research into causes, diagnosis, various treatments and outcomes of CRPS and literature into the lived

experience of pain in general [19–22,25,29,51,52], but living with CRPS has not been investigated. It is necessary to do this in order to assess the responses of those living with CRPS to inform health practitioners and enable comparisons and evaluations of treatments. Until an in-depth knowledge of living with CRPS is understood, recommendations on the management of the condition may be inappropriate or ineffective, and may be counterproductive to the actual needs of the CRPS patient.

Brunner et al. [49] performed research into CRPS and the knowledge levels of people diagnosed with it. They found that patients have less than optimal knowledge about their condition and recommended that future research be directed at improving patient education. Rodham et al. [38] reported that some of their participants felt discouragement and reluctance to access local support if they felt practitioner knowledge in CRPS treatment was lacking. Distance from the pool of expertise was a key theme reported by Rodham et al. [38]. These two results confirm the need for positive healthcare experiences provided by knowledgeable practitioners who can educate patients but then provide the non-judgmental support necessary for patients to make their own choices.

6. Conclusion

The aim of this paper was to identify and synthesise the currently available literature on experiences of living with chronic pain in order to understand where and how CRPS research may be best situated in the future. It has been demonstrated there is a paucity of information on living with CRPS and, therefore, chronic pain in general was used as a starting point and the lived experience of chronic pain conditions was reviewed. Fig. 1 shows themes emerging from the data on living and dealing with constant pain and posed the question “where does living with CRPS fit?” Because pain cannot be seen, there can be questions raised by those surrounding the patient as to the reality of the complaint. Not being

believed when a person is in pain can cause emotional distress, stigmatisation, depression and isolation. This can often lead to feelings of loss of the former pain free self, and a complete change in living circumstances. Living with a painful body may require a total life change with sufferers concentrating initially on alleviating the pain and getting treatment. Self-management is an important concept in living life with chronic pain as normally as possible. Living with chronic pain can result in a number of life changes prominent among which are ceasing work and withdrawal from activities and relationships. Some studies highlight that despite the loss of their former lives, some people are able to adapt to a new form of existence.

Until research into the lived experience of CRPS is conducted, we will have only anecdotal evidence on which to base future treatment guidelines.

7. Implications

The International Association for the Study of Pain [47] identified desirable characteristics of national pain strategies which are increasingly being developed throughout the world. IASP acknowledged that patients and their families should be active participants in the process and literature supports the notion that people living with pain may be the best teachers to provide understanding from the patients' perspective [10,38,47]. In order to assist the development and implementation of the national pain strategies, further investigation is required into the experience of pain and especially CRPS; the dearth of literature on the subject supports this recommendation [10,38]. Determining the lived experience of the Complex Regional Pain Syndrome cohort would provide information never before published which would inform patients, practitioners and the general public of previously unacknowledged characteristics of this syndrome. Research should represent the entire patient spectrum and consideration must be given to engaging in conversation about pain using the non-medical words of the patient rather than asking patients to quantify it [11,19].

7.1. Future research

Future research should utilise a semi structured interview process to answer research questions such as:

Research question 1. What is it like to live with CRPS?

Research question 2. What is the impact of CRPS on individuals and families?

Research question 3. What are the health goals of individuals impacted by CRPS?

The interview questions are listed in Appendix B. Further details regarding this research may be obtained by contacting the author.

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Conflicts of interest

There are no conflicts of interest to declare.

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Appendix A.

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** Although these studies included some participants with back pain the majority of the participants did not have back pain, or the participants had pain at multiple sites, and the articles were defined as meeting the criteria for this study.

Appendix B.

- 1 What is it like for you to have CRPS?
- 2 In what way is your life different now to before you developed CRPS?
- 3 Have you made any changes to cope with physical limitations?
- 4 Have you made any changes to cope with mental/psychological limitations?
- 5 How does having CRPS make you feel?
- 6 Are there any financial factors to consider?
- 7 In what ways has CRPS affected your family?
- 8 What do you think health practitioners should know in order to treat you more effectively?
- 9 Have you seen any health practitioners regarding your condition
 - a Who
 - b How long for
 - c Cost
 - d Result
- 10 What strategies and support people do you find most useful in managing your condition
- 11 What are your health goals

12 What are your successes with CRPS – prompt if required – weaning from medication, more movement, regaining confidence

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To date (August 2018) this article has been cited 4 times. When it was published, the editorial comment for that edition of the journal discussed qualitative research and CRPS, commending the article for the patient focused approach taken and recommended additional research questions that could be asked of patients such as treatments they have undergone, effects of treatment side effects, and their most bothersome symptoms (Butler, 2015). This editorial cited a qualitative study (published online ahead of print) looking at the information needs of people with CRPS that had not been discovered during the literature search described above (Grieve et al., 2016). The second citation was by Méndez-Rebolledo, Gatica-Rojas, Torres-Cueco, Albornoz-Verdugo, and Guzmán-Muñoz (2017). The article was cited twice more in 2017 in a qualitative study about persistent pain in adolescents (Sørensen & Christiansen, 2017) and the editorial comment for that issue (Breivik & Butler, 2017).

THE CRPS QUALITATIVE LITERATURE FROM 2015 ONWARD

A literature search was conducted in June 2018 to update the literature base of the thesis with the currently available published literature on living with CRPS.

Methods

Following the experience of the first literature search described above, it was anticipated that few published articles would be found. The search terms used were - complex regional pain syndrome OR CRPS AND lived experience, qualitative, phenomenology and interview.

Databases searched were – PUBMED, Informit, EBSCO, ProQuest, Scopus, Web of Science and Google Scholar.

Inclusion criteria

Inclusion criteria were that the research must be qualitative, the article must be published in 2015 or after and must describe the experience of living with CRPS.

Exclusion criteria

Exclusion criteria were the qualitative component of clinical trials where the primary focus was on treatment effects or medication efficacy and articles not written in English.

Results

A total of 116 papers were identified. After removing duplicates and discarding papers with a title obviously not fitting the inclusion criteria, the abstracts of five papers were examined. In each case, a specific aspect of living with CRPS was a research focus. Of these five, only two met all the inclusion criteria, the aforementioned research by Grieve et al. (2016) which

explored the lived experiences of CRPS to provide insight into the information needs of patients was first. The second result was a Master of Science Thesis (Besa, 2015). Similar to the paper by Grieve et al. (2016), this research used information from lived experience to gather specific data, aiming to provide knowledge to clinicians on how to better provide care and communicate with patients in the clinical setting. The three papers not meeting all the inclusion criteria described the qualitative aspect of a 2-Round Delphi-based study. These papers were included in the final review as the qualitative aspect aimed to define recovery from the patients' perspective (Llewellyn, Birklein, et al., 2018; Llewellyn, McCabe, et al., 2018; Sweeting, Llewellyn, & McCabe, 2018). Two of these papers are poster abstracts.

The decision was made to include another article in the review after the author forwarded it to a member of the supervision team. Although published in 2013, this article had not been discovered in previous searches most likely due to CRPS being the only keyword used. It was written to raise awareness of the condition and to describe the author's experience of living with CRPS (Binkley, 2013). Thus, six articles were reviewed.

Discussion

With the exception of the paper by Binkley (2013), the papers reviewed concentrated on describing an aspect of living with CRPS. The aims of the research conducted were:

- To define recovery from the patients' perspective and provide an understanding of their treatment priorities (Llewellyn, Birklein, et al., 2018; Llewellyn, McCabe, et al., 2018; Sweeting et al., 2018);
- To explore participants' lived experiences of CRPS and gain insight into their world to understand their specific information needs (Grieve et al., 2016);
- To explore the lived experience of CRPS in order to provide knowledge to clinicians on how to communicate and provide care to patients admitted to a clinical setting (Besa, 2015); and
- To provide insight from the experience of a clinical immunologist into barriers to diagnosis and treatment of CRPS.

The six papers had similar results, and these fit within the themes reported by Johnston et al. (2015). This indicates that the themes of disbelief/invisibility of pain, loss, coping with a non-compliant/constant painful body, self-management, and alleviating pain/treatment are applicable in the CRPS population. Living with CRPS appears to incorporate all the difficulties of living with any chronic pain condition but also includes difficulties unique to the condition.

Some of these are the intense, disproportionate pain, the fact that longstanding symptomatic CRPS may no longer meet the diagnostic criteria, and the physical consequences of the condition which are beyond those assessed by the CRPS diagnostic criteria such as spreading (Binkley, 2013; Llewellyn, McCabe, et al., 2018; Sweeting et al., 2018). A constant problem appears to be that CRPS remains a little-known condition of which many health professionals are unfamiliar resulting in difficulty in accessing expert medical care (Besa, 2015; Binkley, 2013; Grieve et al., 2016).

Chronic pain is largely invisible and is often disbelieved (Johnston et al., 2015) yet even though CRPS in its early stages has classic florid, objective signs and symptoms, patients described a delay in diagnosis, disbelief regarding pain levels reported, and disbelief regarding the CRPS diagnosis (Besa, 2015; Binkley, 2013). Accessing appropriate information about CRPS and accessing treatment from knowledgeable health care providers is a problem for all people living with CRPS, including medical professionals (Besa, 2015; Binkley, 2013; Grieve et al., 2016).

Both Grieve et al. (2016) and Besa (2015) accessed participants from CRPS internet sites and report to have used a phenomenological approach to their research and used inductive thematic analysis for the 8 participant interviews each conducted. The research published by Llewellyn, Birklein, et al. (2018), Llewellyn, McCabe, et al. (2018) and Sweeting et al. (2018) was conducted by an international consortium in eight countries and used deductive thematic analysis on the completed questionnaires of between 252 and 347 participants. In four of these five articles, the authors stated they used QSR NVivo in the analysis, whereas Besa (2015) simply stated that codes were generated to form meaning groups which were sorted into themes. The comprehensive account of living with CRPS in this group of articles is the autobiographical article by Binkley (2013), describing her own experience.

Research into defining cure is continuing and to this end, patients reported that relief of pain including generalised pain and discomfort, improved movement, less limb stiffness and reduction in required medication are the most important factors they would consider to deem themselves recovered from CRPS (Llewellyn, McCabe, et al., 2018). Although Binkley (2013) did not define cure or improvement, her “relatively good treatment outcome” (p. 484) is mentioned with the caveat that the treatments and resources accessed “would not be available for the average non-physician patient” (p. 484). This is in keeping with the findings that there is a gap between the information needs of patients and the information available

for them to access and that raising awareness into the condition may help to alleviate this issue (Besa, 2015; Grieve et al., 2016).

The involvement of patient partners in the international consortium research team which included Llewellyn, McCabe, et al. (2018) appears to have provided a unique perspective which should continue as future publications such as the BMJ ask for a statement of how patients were involved in the creation of the article (Bruehl, 2015).

CHAPTER SUMMARY

Little qualitative research has been published about CRPS and chronic pain was used as a starting point for a literature review. Published in 2015, that review revealed that people living with chronic pain experience loss, disbelief, have difficulty coping with a painful body and must find treatment and strategies to self-manage. The literature review was updated in 2018 which indicated that there remains a gap in the published literature about living with CRPS, as to date, the essence of living with the condition has not been researched. The methodology used in this research to help fill this gap will be discussed in the next chapter – Methodology and Methods.

CHAPTER 3: METHODOLOGY AND METHODS

INTRODUCTION

The research methodology used throughout this study is presented in this chapter.

Methodology is the theory behind the method; the macro-level framework which provides a research strategy, influencing the choice of what method should be followed (O'Leary, 2012; van Manen, 1990). When deciding on a methodology for this thesis, I utilised a pragmatic approach as described by Punch (2009) whereby I started with the research question and chose the most appropriate method to answer it. To understand the essence of living with CRPS a quantitative approach was considered unlikely to reveal the depths of description of lived experience required. I considered many qualitative approaches and fully agree with Patton who said, "the diversity of qualitative enquiry frameworks has created both opportunity and confusion" (2015, p. 97).

The aim of this study was to understand the phenomenon of chronic pain in the lifeworld of people living with Complex Regional Pain Syndrome (CRPS). The research question was:

What is chronic pain in the lifeworld of complex regional pain syndrome?

There were several options available to answer the research question and explore the phenomenon of chronic pain in the lifeworld of those with CRPS. Quantitative approaches such as surveys were considered restrictive in that responses are limited to the questions asked. A qualitative approach was considered more appropriate as this research is seeking to explore human experience. The qualitative approach allows participants to offer additional data and clarification and provide depth in telling of their experiences to achieve an intimate understanding of the phenomenon under investigation (O'Leary, 2012). As my aim was to understand the essence of a phenomenon rather than generate theory, grounded theory was not considered. I wanted to use my own story in the research but tell more than just my own story and therefore autoethnography was also not considered.

Hermeneutic phenomenology was chosen as it aims to find meaning and is the study of phenomena utilising lived experience of the phenomenon as data (Dowling & Cooney, 2012; van Manen, 1990). I also aimed to provide an insider perspective of living with chronic pain and to achieve this, elements of heuristic inquiry were included so that I could include data from my own experience without allowing that experience to dominate the research.

To gain a thorough understanding of the philosophical underpinnings of my research, I researched and co-wrote a paper with my supervisors. This paper (Johnston, Wallis, Opreescu, & Gray, 2017) suggests that a heuristic hermeneutic phenomenological approach is appropriate and that data from the researcher's experience can be used in explicating pre-understandings and assumptions, and to access additional data related to the lived experience of the phenomenon. I followed the approach identified in the paper to ensure the methodological considerations of usability, credibility, auditability and trustworthiness to ensure rigour in the research. I will now discuss the qualitative approaches used in this research in further detail.

PHENOMENOLOGY

Phenomenology began as a philosophical approach to understanding life and living and was first used in social science by Edmund Husserl (1913-1954), a German philosopher (Converse, 2012; Patton, 2015). Husserl espoused a descriptive or eidetic form of phenomenology, where a description is given of the general characteristics, to determine the meaning or essence of the phenomenon (Converse, 2012; Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). In an attempt to explain everything as products of consciousness, Husserl believed in setting aside or bracketing natural assumptions in order to describe the phenomenon in its purest form. This setting aside of the natural attitude to the philosophical he called phenomenological reduction (Converse, 2012; Tuohy et al., 2013; Walters, 1995).

In contrast to the descriptive phenomenology described by Husserl, his student Martin Heidegger (1889-1976) developed a phenomenological method for being-in-the-world, rejecting the notion of bracketing and suspending one's own presuppositions and advocating using one's own lived experience for interpretation (Dowling & Cooney, 2012; Mackey, 2005; Walters, 1995). While Husserl formulated the notion of the lifeworld, as the world of lived experience, or the world that is already there (van Manen, 1990), Heidegger extended this notion, developing an existential phenomenology which aims to describe "how phenomena present themselves in lived experience" (van Manen, 1990, p. 184). Heidegger's existential phenomenology is also often referred to as ontological phenomenology (concerned with being) while Husserl's transcendental phenomenology is epistemological (concerned with knowledge and the cogito) (van Manen, 2011).

Other scholars have further developed the work of both Husserl and Heidegger such as Maurice Merleau-Ponty (1908–1961, existential phenomenology), Hans-Georg Gadamer

(1900-2002, hermeneutics), Paul Ricoeur (1913-2005, phenomenological hermeneutics), and Amedeo Giorgi 1931- , phenomenology and humanistic psychology). Thus, over time, the phenomenological movement has undergone various transitions and today there are many schools or branches of phenomenology in existence. The first such scientific community was known as the Utrecht School in Holland and members used a phenomenological approach to describe how psychological and other human phenomena were lived (Giorgi, 2017).

There were two off shoots of this school in North America, one of them was led by Max van Manen who developed the work of the Utrecht school for the discipline of pedagogy (Giorgi, 2017). The interpretative school uses descriptions of lived experience as data to describe the essence of a phenomenon. For example, Manning (2014) used the models of van Manen and Moustakas to find the essence of spiritual resilience to be a “process where the mechanisms of divine support, purpose, and gratitude, work together to create experiences of enduring hardships over the life course” (p.360). In contrast, the other school, sometimes labelled North American, aim for descriptions of lived experience such as diabetes (George & Thomas, 2010), and penis cancer (Gordon, LoBiondo-Wood, & Malecha, 2017). Rather than define an essence, George and Thomas (2010) explained the experiences and perceptions of self-management of diabetes and Gordon et al (2017) related the perspectives of being diagnosed and treated for penis cancer .

While phenomenology began as a philosophy, it can also be considered a psychotherapy approach, a qualitative tradition, a research methods framework and an analytical perspective which causes confusion and debate, particularly concerning the practice of phenomenological research (Giorgi, 2017; Paley, 2018a; Patton, 2015). The fact that Foucault is labelled a phenomenologist even though he denied it, exemplifies some of the debates surrounding phenomenology (van Manen, 2011). Authors such as Crotty (1996), and Paley (2005) are critical of research works, particularly in the nursing field, being described as phenomenological although Darbyshire, Diekelmann, and Diekelmann (1999) refute the ideas of Crotty, and Petrovskaya (2014a, 2014b) believes Paley was misread, stating that Paley believed that North American or ‘new’ phenomenological nursing researchers incorrectly attribute Continental or European phenomenological thought to their current work.

Crotty (1996) too believed phenomenology in the North American nursing tradition to be different from European phenomenology and more a combination of pragmatist philosophy, humanistic psychology and symbolic interactionism. His main concern according to Barkway (2001) was that a phenomenon is not the same thing as a person’s experience of a

phenomenon and that nurse researchers were not recognising the difference. Crotty (1996) used 30 examples of nursing research to demonstrate this belief that nursing phenomenologists are researching human subjects rather than engaging with a phenomenon and was highly critical of them. One of the major criticisms of Crotty's work was that he himself misunderstood the intention of Heidegger (Darbyshire et al., 1999). Crotty and Paley are both criticised by Giorgi (Giorgi, 2000a, 200b, 2017).

Phenomenologist Amedeo Giorgi (2000a) believed that researchers do not always clarify their understandings of phenomenology and stated that an unscholarly Crotty missed the distinction between scientific and philosophical phenomenology. If Giorgi (2000a) claimed Crotty displayed poor scholarship, he was even more scathing of Paley (Giorgi, 2000b, 2017) who he described as unsympathetic, careless, and as someone reading phenomenology only for the purpose of critiquing it. Paley (2005) believed nursing phenomenology could not meet the criteria espoused by Husserl but according to Giorgi (2000b) nurses would be practising philosophy if they did. Paley was also accused of not giving the phenomenological movement, which began in the 1950s and 1960s, time to develop, treating a young discipline as a mature tradition (Giorgi, 2017). Paley in response to criticisms of his work wrote responses to both van Manen (Paley, 2018a) and Giorgi (Paley, 2018b) claiming the articles they wrote in response to his book *Phenomenology as Qualitative Research: A Critical Analysis of Meaning Attribution* are "studies in misreading" (Paley, 2018a p. 1). Thus, Paley accuses both van Manen and Giorgi, and they accuse Paley, of misreading Heidegger, misunderstanding Husserl and misreading the work of each other.

Giorgi (2000b) stated he would prefer to motivate researchers to do better phenomenological research and to this end he recommended that human scientists should demonstrate good scholarly practice by identifying the philosopher from which came the greatest inspiration and modify their thoughts to be meaningful to the phenomenological context of use. It is within the work of van Manen that this study is situated. van Manen (1990), aiming to be relevant to nurses, psychologists and teachers researching human science, uses the terms human science interchangeably with phenomenology and hermeneutics and describes an approach to human science research which he believes shows "a semiotic employment of the methods of phenomenology and hermeneutics" (p. 1). For van Manen (1990), phenomenology aims to transform a description of lived experience into a textual representation of its essence using the existentials of time, body, space and relations. Therefore, this approach was deemed best suited to answer the research question.

HERMENEUTICS

Hermeneutics is also known as interpretative phenomenology and proponents claim there are no such things as uninterpreted data. People who engage in hermeneutics attempt to be descriptive; letting things speak for themselves and being attentive to how things appear (van Manen, 1990). Acknowledging that the “(phenomenological) facts of lived experience are already meaningfully (hermeneutically) experienced” (van Manen, 1990, p.181), such researchers aim to describe, understand and interpret the experiences of the participants (Tuohy et al., 2013; Walters, 1995). The hermeneutic researcher is considered inseparable from their assumptions and preunderstandings and is encouraged to interpret the data through a process of the hermeneutic circle; creating meaning from the participants’ experiences and the “being of the researcher coming together” (Converse, 2012, p. 32).

HEURISTIC INQUIRY

Situated within the phenomenology framework, hermeneutics retains the essence of the person in human experience, embracing self-experience rather than detaching from it (Moustakas, 2011; Patton, 2015). Some of the important elements of heuristic inquiry that differ from phenomenology are the personal experience and intense interest of the researcher in the phenomenon under study, and, the others who are part of the study must also share an intensity of experience with the phenomenon (Patton, 2015). Clark Moustakas (1923-2012) considered the primary developer of this approach, identified immersion, incubation, illumination, explication, creative synthesis and validation as the essential elements and stages of heuristic inquiry (Moustakas, 2011).

THE HEURISTIC HERMENEUTIC PHENOMENOLOGICAL METHOD

Within the broader paradigm of interpretative qualitative research, the overarching framework chosen for this research is phenomenology, complemented by hermeneutics and heuristic inquiry. The evolution of phenomenology as a research approach has evolved over time and there is no single way to conduct such a study as it is considered to be free from prescriptive methodology (Dowling & Cooney, 2012). According to (van Manen, 1997 , p.29) “the method of phenomenology and hermeneutics is that there is no method”. This quote gave me the freedom I needed to incorporate elements of heuristics which “permits and even encourages spontaneous creation of methods that will evoke or disclose experiential meanings” (Douglass & Moustakas, 1985, p.49).

I live with Complex Regional Pain Syndrome, having been diagnosed with the condition in 2010, therefore, the research question is personal, and my experience is an important data source. Heuristic inquiry then is appropriate as “in heuristic inquiry, the research question chooses you, and invariably, the research question is deeply personal in origin” (Patton, 2015 p. 119). To immerse myself fully in the phenomenon of living with chronic pain as described by Moustakas (2011, p. 6) however, would not be healthy:

“The heuristic research process is not one that can be hurried or timed by the clock or calendar. It demands the total presence, honesty, maturity, and integrity of a researcher who not only strongly desires to know and understand but is willing to commit endless hours of sustained immersion and focused concentration on one central question, to risk the opening of wounds and passionate concerns, and to undergo the personal transformation that exists as a possibility in every heuristic journey”.

If I think about my affected hand, especially when it is hurting, the pain increases. I was not prepared to commit to the level described by Moustakas but was prepared to examine my own experience to a lesser degree.

PUBLICATION

I chose to utilise elements of heuristics in a hermeneutic phenomenological approach as described in the following published article: Methodological considerations related to nurse researchers using their own experience of a phenomenon within phenomenology. This article provides a summary of phenomenology and offers a discussion on how the researcher may use their own lived experience of a phenomenon to explicate their assumptions and pre-understandings. The article describes how a researcher may also use their own experience as a source of data alongside that of other research participants in order to gain a complete picture of the phenomenon under investigation. It outlines an approach which may be taken to ensure the methodological considerations of credibility, trustworthiness, usability and auditability and that philosophical choices are made explicit to ensure rigour in the research while maintaining orientation to the phenomenon. It has been cited ten times (to August 2018). The article is presented in the format as it was published in the Journal of Advanced Nursing, including the reference list. The original page numbers have been retained and the thesis page numbers added.

DISCUSSION PAPER

Methodological considerations related to nurse researchers using their own experience of a phenomenon within phenomenology

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Abstract

Aims. This paper summarizes phenomenology and discusses how nurses can use their own experiences as data and maintain rigour within the method. It explores how data from researchers experiencing the phenomenon of interest could be used to explicate assumptions and pre-understandings and may also be used as data.

Background. While the ethnographic concept of insider research has gained popularity, the notion of researcher as participant in phenomenology is relatively new. The lived experience of a phenomenon is unique to each person and utilization of the nurse researcher's experiences of the phenomenon should be considered for inclusion as data.

Design. Discussion paper.

Data sources. Articles from 2001 - 2015 in the CINAHL and PubMed databases were identified using keywords such as 'insider research', 'phenomenology', 'bracketing' and 'qualitative research'. In addition, reference lists from articles used were examined to identify additional literature.

Implications for nursing. Phenomenology is a valuable research method. Usability, credibility, trustworthiness and auditability of data collected must be considered to ensure rigour and maintain orientation to the phenomenon under investigation. Nurse researchers may be interviewed as participants if these four principles are considered and methods used are made explicit. Utilizing appropriate research methods are as important as getting clinical practice correct to advance knowledge and benefit those under our care.

Conclusion. We recommend using the researchers' experience as a data source to gain a complete picture of the phenomenon under investigation. Using the approach proposed here, nurses can ensure they are incorporating all data sources available while maintaining research rigour.

Keywords: nursing research, qualitative research, phenomenology, heuristic inquiry, hermeneutics, trustworthiness, auditability, lived experience, bracketing, insider research

Why is this research or review needed?

- Qualitative research is sometimes criticized as being a non scientific method due to the potential for researcher bias. Methods to address potential bias include reflexivity and acknowledgement of researchers' 'insider' status.
- Use of the researchers' own data has not been extensively explored in methodological literature.
- This paper discusses key concepts to consider when utilizing the researcher as a participant as a way to ensure quality of the qualitative research process.

What are the key findings?

- A nurse's own experience can be an important data source, can be used as data and may explicate the researchers' assumptions.
- The nurse researcher can be used as one of the research participants and the data can be used alongside data from participants, having the same status.
- The major risk to be aware of is that data from the nurse researcher can be used as the organizing framework for analysis.

How should the findings be used to influence policy/practice/research/education?

- Usability, credibility, trustworthiness and auditability of data should be used to ensure quality of research.
- The approach we propose could be considered when the experience of the researcher is to be incorporated into the data allowing for completeness of data collection recognizing multiple realities.

Introduction

Phenomenology is the study of meaning, used to understand an experience from the perspective of those who are having it (Cohen 2000). It asks: 'what is the meaning, structure and essence of the lived experience of this phenomenon for this person or group of people?' (Patton 2015 p. 115). Phenomenology and its use as a research method has been evolving over time. It began as a philosophical approach to understanding human life and living. Moving on from the positions of Husserl and Heidegger, Merleau-Ponty, Gadamer and Ricoeur all published extensively in the philosophical literature (Cohen 2000, Converse 2012, Dowling & Cooney 2012). More recently, van Manen (1990) has explicated an approach to using phenomenology as a method; he has written extensively on the subject of researching lived experience.

To understand fully a human experience, it is necessary to access it through the subjective lens of the people

experiencing it (Karp 1996). The necessity for nurses to understand the experience of others makes phenomenology ideally situated as a research methodology for the nursing profession and there has been a growing acceptance of phenomenology in nursing (Cohen 2000, Le Vasseur 2003). Discussion and debate continues however, regarding the methods utilized by nurses underpinning the approach (Rose *et al.* 1995, Crotty 1996, Le Vasseur 2003, Mackey 2005). Authors often discuss the differences between the work of the philosophers Heidegger and Husserl (Mackey 2005, Converse 2012, Dowling & Cooney 2012, Heinonen 2015a) and debate the focus of phenomenology, whether it is lived experience or phenomena; what constitutes phenomenological data; and, its usefulness as a technique (van Manen 1990, Crotty 1996, Cohen 2000, Paley 2000, Petrovskaya 2014a, Patton 2015). One issue about which the debate is ongoing is the role of the researcher's lived experience and how this should be used and managed within phenomenology.

A criticism of qualitative research methods, not just phenomenology, is that of bias of the researcher (Kahn 2000). While some texts support the notion that preconceptions and presuppositions, or subjective association with the topic under investigation will inevitably bias the interpretation of the data, others argue that there is no such thing as uninterpreted data (van Manen 1990, Crotty 1996, Kahn 2000, Nielsen 2007). While bracketing or suspending their own assumptions and beliefs is a way of allowing researchers to focus solely on the data gathered, some authors query that assumptions can be put aside and believe that researchers' frames of reference always influence the interpretative process (Crotty 1996, Le Vasseur 2003).

Researchers drawing on their own experience of a phenomenon, in particular, is open to criticism of this nature due to the close relationship of the researcher with the research data. The purpose of this paper is to discuss how data from researchers drawing on their own experience could be used to both explicate assumptions and pre-understandings (van Manen 1990) (sometimes referred to as bracketing) and to access description of lived experience. While using data in these ways, it is necessary to ensure the rigour of the process such that the findings can be accepted as credible and transferable (Sandelowski & Barroso 2007).

The use of a researcher's experience as research data is well accepted and described in other qualitative methods such as anthropology and autoethnography. Another method, heuristic inquiry, is grounded in phenomenology and utilizes the personal experience and insights of the researcher in reports (Patton 2015). In this article, the appropriateness of and approaches to using the researcher's

own experience of a phenomenon in a phenomenological study will be examined. In particular, not only the experience of the researcher as a nurse who has assisted people with first-hand experience of a phenomenon but also the nurse as someone who has personal first-hand lived experience of the phenomenon.

Background

In designing, a research project researchers must choose the method that is most appropriate to answer the research question while also considering which approach will make best use of their own particular knowledge and experience of the phenomenon under consideration to achieve credibility (Rose *et al.* 1995, Dowling & Cooney 2012). Many authors agree that phenomenology is an appropriate interpretative methodological research approach for nurses (Rose *et al.* 1995, Crotty 1996, Todres & Wheeler 2001, Mackey 2005, Converse 2012, Heinonen 2015a). Patricia Benner (who wrote about the development of clinical competence) and Rosemary Parse (theory of human becoming), are well known nurse phenomenologists (Crotty 1996, Mackey 2005, Polit & Beck 2012). A more recent example of a nurse phenomenologist is Heinonen (2015b) who used van Manen's phenomenological hermeneutic method to describe the lifeworld of multiple birth families in Finland. It is generally agreed that phenomenology is the method of choice when investigating phenomena using lived experience of a phenomenon as data (van Manen 1990, Baker *et al.* 1992, Dowling & Cooney 2012).

It is recognized that nurses engage with patients' lived experiences of health and illness every day (Le Vasseur 2003) and description of human experience is 'foundational to practice' (Todres & Wheeler 2001, p. 2), yet little recognition has been paid to the fact that nurses themselves have their own experiences of health and wellness. By extension of that notion and acknowledgement that 'a good phenomenological description is collected by lived experience and recollects lived experience—is validated by lived experience and it validates lived experience' (van Manen 1990, p. 27), it would seem remiss to not utilize the lived experiences of nurse researchers themselves if they have experience of the phenomena under investigation.

This paper will now provide a discussion of how the researcher's own lived experience of a phenomenon could be used to both explicate assumptions and pre-understandings (van Manen 1990) and to access description of lived experience. It will also address the question of what determines quality in qualitative research and, suggest ways that nurses use their own data and maintain the standards of quality.

Data sources

A literature search using the terms insider research, bracketing, phenomenology and qualitative research was conducted using the CINAHL and PubMed databases. Although 'insider research' is an ethnographical term, these articles discussed the issue of utilizing data from the researcher's own experience and therefore were considered appropriate for inclusion. Five hundred and seventy-nine articles written in English from 2001 until 2015 were retrieved and reference lists of articles were also examined to obtain additional material. Methodological articles from peer reviewed journals relevant to nursing research were prioritized and after duplicates were removed and abstracts reviewed, 72 articles were identified as appropriate for further examination.

Further selection criteria included:

- Seminal works and discussion papers on the development of methodological approaches and methods. Ten books were included at this stage.
- Discussion and/or comparison papers related to issues in methods such as rigour and bracketing.
- Papers focusing on methodological debates and controversies such as method slurring and what is phenomenology.
- Papers describing use of personal experience.

Papers were excluded if they described studies not including personal experience and those that described the use of other research methods (except where the method used was compared with phenomenology). Forty-two references met the criteria for review.

Discussion

The place of the researcher's experience in qualitative methods

Qualitative methods address the issue of using personal experience in different ways. For example in ethnography, researchers who have experience with the culture under investigation are often referred to as insider researchers (Wilkinson & Kitzinger 2013). Autoethnography, originating in ethnography, is also known as insider research; written subjectively and combining personal experience and research techniques (Ellis *et al.* 2011, Polit & Beck 2012, Hogan 2013).

There is no term dedicated in phenomenology to describe the researcher using their own experience as data. Heidegger uses the term Dasein as the entity of 'Being', which we label ourselves and the reader is directed to his work for a

comprehensive understanding of this concept (Mulhall 1996). Pre-understandings and assumptions can also be described as the researchers' common sense, presuppositions, preconceptions and prejudices (van Manen 1990, Todres & Wheeler 2001). If we do not acknowledge what we already know about a phenomenon, our thoughts may inadvertently affect our reflection. Acknowledging what we already know can be achieved through such means as bracketing, reduction, reflexivity, reflection and use of a reflective diary and the researcher may also wish to be interviewed. Each has merit and the use of one does not preclude simultaneous use of another.

Bracketing, used in descriptive or Husserlian phenomenology to ensure trustworthiness and limit bias, involves being self-aware or freeing oneself of assumptions and making the researchers own perspective explicit and putting this knowledge aside (Rose *et al.* 1995, Polit & Beck 2012, Heinonen 2015a). The bracketing interview, described by Pollio *et al.* (1997) is an attempt to identify preconceptions whereby the researcher undergoes an interview with the research team prior to interviewing study participants.

The concept of bracketing was conceived by Husserl (1931). He describes the natural standpoint as imagining, judging, feeling and intuitively experiencing the world. He believed we had to suspend our thoughts, or natural standpoint stating:

We do not abandon the thesis we have adopted, we make no change in our conviction, which remains in itself what it is so long as we do not introduce new motives of judgement, which we precisely refrain from doing. And yet, the thesis undergoes a modification – whilst remaining in itself what it is, we set it out as it were 'out of action' we 'disconnect it', 'bracket it'. (Husserl 1931, p. 57).

Thus, Husserl included the full human conscious experience when describing bracketing as the suspension of one's natural assumptions of the world (Le Vasseur 2003). Husserl was criticized as being an idealist by existentialists for his attempts to describe the essence of phenomena and the implication of a priority of essence over existence (Le Vasseur 2003). He introduced the terms reduction and epoché to describe a new way of looking at things, stripped of everything empirical, following the removal of all consciousness (Husserl 1931). Heidegger disagreed with the notion of phenomenological reduction, holding that as consciousness cannot be separated from existence it is impossible to bracket prior conceptions and knowledge (Le Vasseur 2003). However, Husserl though did not advocate a permanent denial of theories and knowledge, only a temporary suspension (Husserl 1931, Le Vasseur 2003).

Relationship between phenomenology and heuristic inquiry

According to the Cambridge Dictionary (Cambridge Dictionaries Online 2015), heuristics is a way of solving problems by discovering things yourself and learning from your own experiences. Heuristic inquiry has been described as situated in phenomenology (Crotty 1996, Patton 2015) although Douglass and Moustakas (1985) believe there are several points of difference between the two. Importantly for the focus of this paper, they suggest that heuristics retains the essence of the person in the experience rather than the essence of the experience which is the endpoint of phenomenological inquiry. Moustakas is credited with being the primary developer of this approach (Patton 2015). While authors such as Langdridge (2007) and Heinonen (2015a) argue that van Manen's method should be seen as heuristic, or at least standing in the same tradition (Crotty 1996), there is a persistent problem in qualitative research of naming and differentiating methods as though there are clear boundaries between them. Methods are always accommodated to the practice of research (Sandelowski 2010). van Manen stated 'In drawing up personal descriptions of lived experiences, the phenomenologist knows that one's own experiences are also the possible experiences of others'(van Manen 1990, p. 54).

Heuristic inquiry requires the researcher to have personal experience with and intense interest in the phenomenon under study, the foundational question being 'what is my experience of this phenomenon and the essential experience of others who also experience this phenomenon intensely?' (Patton 2015). Thus, an approach to using the researcher's own experience can utilize the essential elements and stages of heuristic inquiry: immersion in the theme, acquisition of data and realization as described by Douglass and Moustakas (1985). We propose that an approach can be developed that incorporates elements of heuristic inquiry which also includes ways researchers have managed their own experience in phenomenology (Wilkinson & Kitzinger 2013). The researcher needs to determine the extent to which their experience will be used and as Wilkinson and Kitzinger (2013) outline there are several options (Figure 1).

The relationship between the use of personal experience and reflexivity

Reduction as described by (van Manen 1990, p. 185) incorporates heuristic ideals and is the returning to the essential structure involving several levels:

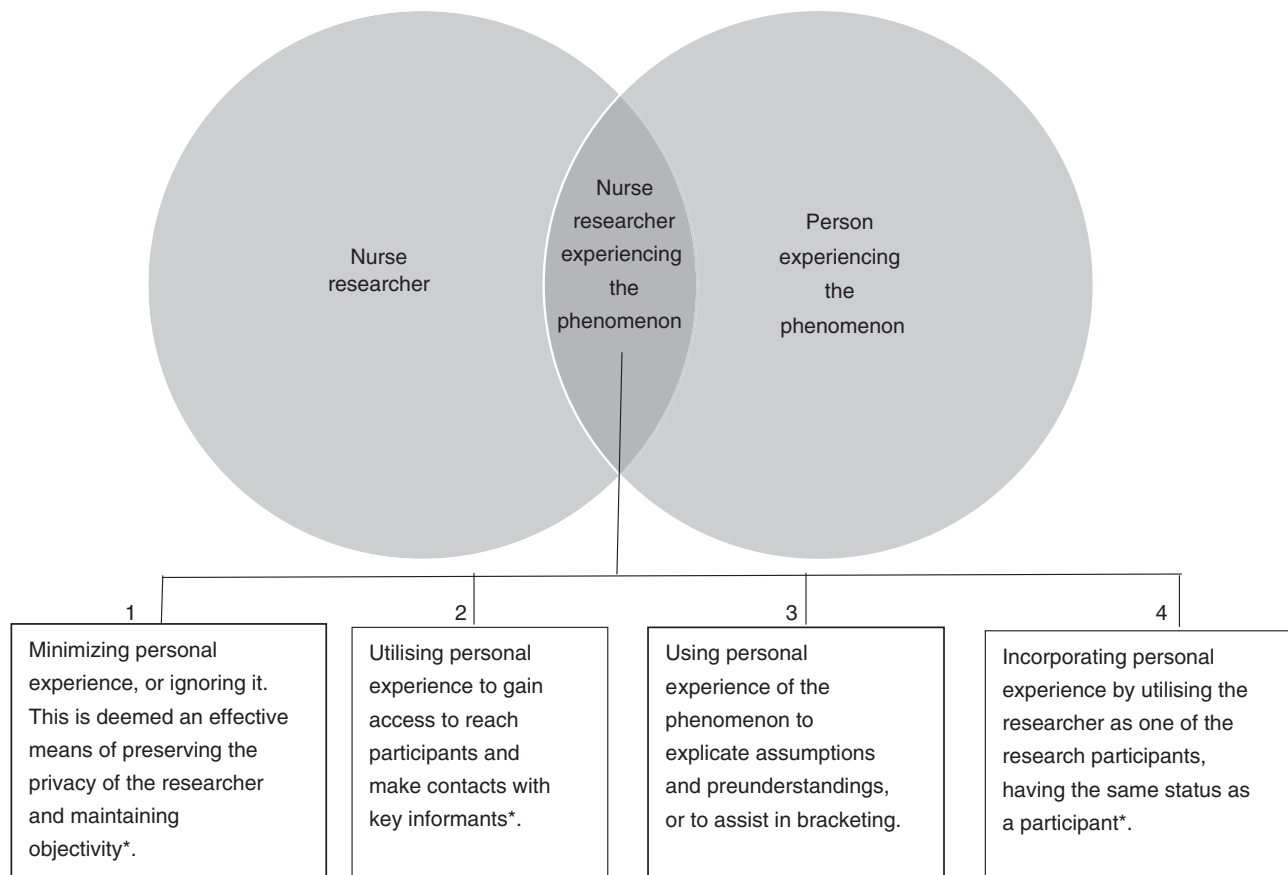


Figure 1 Positioning of researcher as person experiencing the phenomenon under consideration *(Wilkinson & Kitzinger 2013).

- Awakening of wonder.
- Overcoming one's own expectations.
- Stripping away anything preventing the phenomenon from being seen in a non-abstract manner.
- Seeing past the lived experience towards the universal.

Thus, the phenomenon is broken down to the essence; seen without prejudice or theories, in its' purest form (van Manen 1990).

Reflexivity is deep introspection, a critical self-exploration and ownership of one's perspective (Patton 2015). This process enables distance from the researchers' own experience so that interpretation of data is not coloured, but allows for later use of that experience to deepen understanding (Todres & Wheeler 2001). Hermeneutic or interpretive phenomenology recognizes that the researcher has prior understanding and internal suppositions are identified but not bracketed out; rather it is acknowledged that personal knowledge is ever present (Dowling & Cooney 2012, Polit & Beck 2012, Heinonen 2015a). 'As Heidegger himself emphasized, no interpretation of a text can be devoid of preconceptions and value-judgements' (Mulhall 1996 p. xi).

Nurse researchers and the use of personal experience in phenomenology

Todres and Wheeler (2001) believe that hermeneutic issues such as the researcher's presuppositions and prejudices are not always adequately addressed in nursing research. We posit that utilizing some elements of heuristic inquiry might be a more appropriate theoretical tradition, where to base some nursing research, as it brings the personal experience and insights of the researcher to the forefront.

There is a case for the use of the researchers' lived experience as data in nursing research and we should value our own experiences as much as the experiences of the participants because insiders can offer valuable insights unavailable to outsiders (Vickers 2002, Peterson 2015). For this reason, we suggest that the researcher's experience can be accessed and used in the following ways. First, it may be used to explicate pre-understanding and assumptions (van Manen 1990) related to the phenomenon and second, it can be used as data to be analysed alongside the data from participants (Figure 2). This strategy potentially reduces the power differential, putting the researcher's voice on the

same level as the participants (Wilkinson & Kitzinger 2013). A third way might be to discover new sources for informing research activities; using personal experiences as suggested by van Manen (1990, p. 155). Three examples of nurses utilizing their own experience as data are provided in Table 1.

Authors such as Adams (2007) and Ellis *et al.* (2011) explain the inclusion of the researcher's lived experience as data clearly situates the researcher within the phenomenon of interest. The inclusion of the researcher as an interview participant fits into a phenomenological approach, as the interview serves to gather rich data to garner a deeper understanding of a phenomenon (van Manen 1990). There are risks to this approach, however, for example Yost and Chmielewski (2013) utilized Yost as a research participant in their study which was grounded in feminist values and a constructionist, phenomenological epistemology. As Yost was interviewed first, her interview was used in the identification of themes and had a greater influence in shaping the interview protocol doubling her contribution to the research (Wilkinson & Kitzinger 2013).

Those who debate the use of the researcher's own experience contend that it allows for the ideas and experiences of the researcher to be included but, if the only voice heard is that of the researcher, the participants do not get a chance to be heard and the plurality of experience existing in any

group is not recognized (Guzik 2013, Wilkinson & Kitzinger 2013). Therefore, the methodological considerations related to data collection in Figure 3 must be adhered to produce high quality qualitative research. A key aspect for ensuring plurality is the concept of rigour, which is the means by which competence and integrity are demonstrated (Tobin & Begley 2004).

Rigour in phenomenology

While situating phenomenology within the broader paradigm of interpretive qualitative research it is important to acknowledge the debate about the issues related to rigour in qualitative research. In response to the critique that all qualitative research is subjective, biased and cannot be trusted to advance our knowledge Guba and Lincoln, in the 1980s, introduced criteria to determine trustworthiness (Morse 2015). They suggested various strategies that could be utilized to ensure trustworthiness: dependability, credibility and transferability (Morse 2015). Over the last 35 years, there has been great discussion and debate related to these issues and additional concepts such as reliability, accuracy, reducing bias, usability and auditability have been debated (Kahn 2000). Recently, Morse (2015) has suggested a return to the social science terms – rigour, reliability, validity and generalizability and notes that strategies to

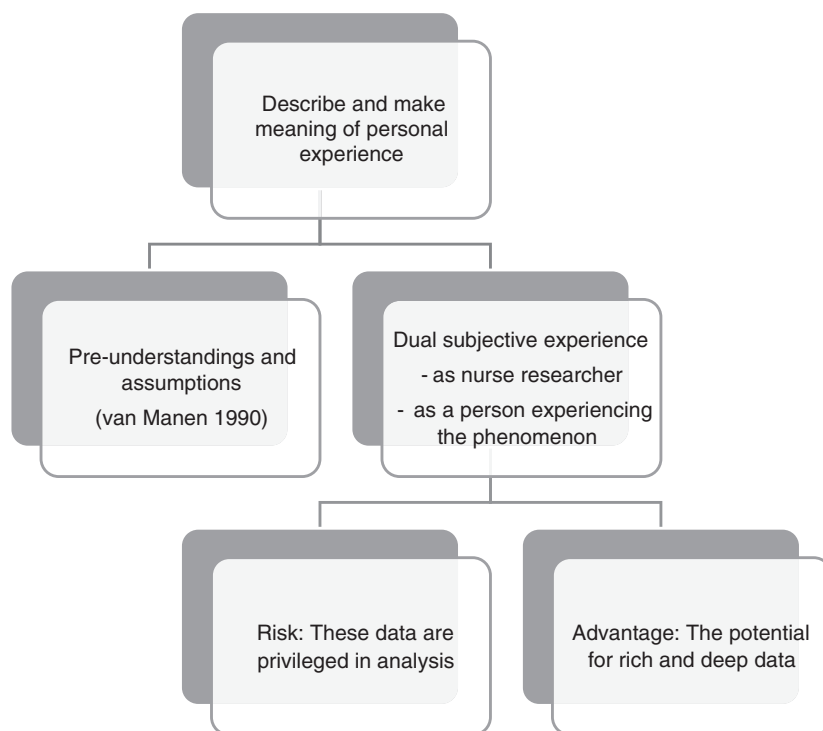


Figure 2 Key areas of focus for nurse researchers when using their own experience of a phenomenon within phenomenology.

Table 1 Nurses utilizing their own experience as data.

Author	Research
Moore (2012)	Moore discussed issues she encountered when as a lecturer and researcher, she observed the actions of nurse lecturers facilitating problem-based learning in seminars in higher education as an 'insider' researcher
Adams (2007)	Adams acknowledged that she had insider status as a nurse who had worked in nursing homes and included herself as a participant in her research after considering various forms of autoethnography. She was interviewed by her supervisor using the same interview schedule used on the participants in her research stating that this lead to a closer examination of her position. The participants were made aware of her insider status which she states had a positive effect on the interviews.
West <i>et al.</i> (2013)	Registered Nurse West inadvertently became an 'insider researcher' when she sustained a back injury while completing her PhD on chronic pain. She felt as if the participants were telling her story as their experience was very much like her own and now believes that 'researchers without some insider knowledge will never come to realize the richness of a phenomenon that can be achieved with insider understanding' and acknowledges that 'the relationship between the researcher and participant is far more complicated than indicated in the literature' p. 64.

ensure trustworthiness or rigour may not be suitable for all qualitative research methods.

Traditionally, phenomenologists have exercised methodological rigour through maintaining orientation to the phenomenon and in the application of the 'hermeneutic circle'. The hermeneutic circle has had a long history and the term has certainly been used in different ways over time (Crotty 1996). The hermeneutic circle is taken in a Heideggerian sense to mean that moving back and forth between the ontic and the ontological facets of the phenomenon that helps to ground and deepen the interpretation. As neither the whole text nor individual part can be understood without the other, it is necessary for both the writer to include these movements and for the reader to enter into a dialogue with the text for a more complete interpretation to occur. van Manen (1997) believes phenomenology engages readers by enriching perspectives through placing the phenomenon in the lifeworld so that the reader can experientially recognize it. By evoking an experience to make it present, a phenomenological text can intensify meaning so that the reader undergoes a transformative experience, reading, reflecting and making meaning through interacting and experiencing

epiphanic moments as the text speaks and validates experience (van Manen 1997).

Phenomenology does not produce empirical accounts, it offers instead, an understanding of the human experience to discover the common meanings underlying the given phenomenon; accounts of experience as it is lived (van Manen 1990, Baker *et al.* 1992). The results may only be representative of the sample studied but generalizability as proposed by Johnson (1997), can be explained as vertical and horizontal. Vertical generalizability illuminates existing theory and horizontal generalizability demonstrates that findings are applicable across settings. Thus, qualitative research contributes to vertical generalizability in that the research can be directed towards building interpretative theory, provided the researcher has considered the study sample when considering the aims, strengths and limitations of a study and, if appropriate, the findings may be applied across settings (Johnson 1997).

As phenomenology strives to understand the essence of a phenomenon, within the method rigour is achieved by examining usability, credibility, trustworthiness and auditability (Figure 3). This is especially important when a researcher is also a participant in the study (Baker *et al.* 1992, Converse 2012, Dowling & Cooney 2012). The terms used in Figure 3 were chosen as they reflect language used throughout literature regarding rigour in phenomenology. Credibility refers to demonstrating truth in the reporting of the research findings. Auditability can be used to demonstrate lack of bias. An audit trail where others can examine the documentation of data and the decision-making processes employed in data analysis often relies on reflexivity and accounts of the research process (Tobin & Begley 2004). An emphasis on trustworthiness by taking account of multiple perspectives and by being balanced was suggested by Lincoln and Guba to replace the traditional mandate to be objective (Patton 2015). The use of the term usability is in reference to employment of the chosen method and its' philosophical base.

There are two ways phenomenological research answers the call for methodological rigour. First, an exploration of the philosophical bases of the method being employed is undertaken. The dialectical relationship that exists between question and method (van Manen 1990) continues through all phases of the research. The level of ontology of the phenomenon in question has to be explored in conjunction with the ontological fitness of the method employed. The ways data are collected, experiences are reflected on and interpretations fashioned need to be in congruence with the philosophical underpinnings of the method employed. For the exploration to be undertaken, each researcher has to explore fully, not only the philosophy they choose but also

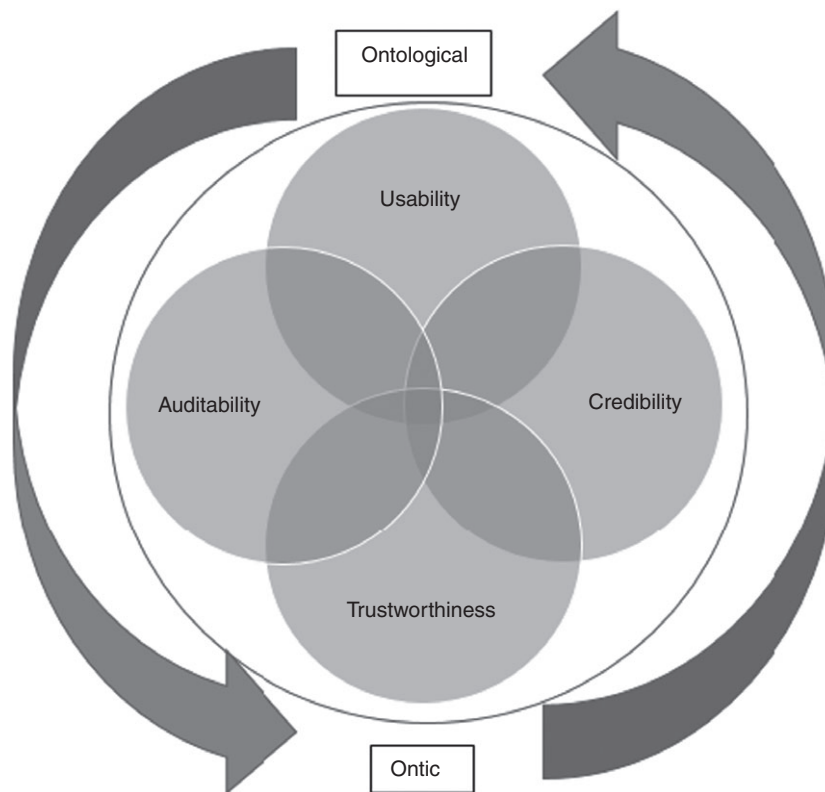


Figure 3 Four key methodological considerations related to data collection, analysis, interpretation and reporting in phenomenological research.

the aims and possibilities of the research they intend to undertake.

The second way phenomenological research ensures methodological rigour is inherent in the writing of research reports. Strategies demonstrating credibility such as verbatim quotes from participants and audit trails allow readers to interact with the data and audit the authors' interpretation thus to follow the evolution of the interpretation (Tobin & Begley 2004). Qualitative nurse researchers such as Sandelowski and Barroso (2007) and Koch (1994) have used terms such as 'auditability', 'audit trail' and 'decision trail' to describe the way the reader is given access to the manner in which the researcher has interacted with the research process. Whether and how this audit trail should include all aspects of the researcher's influence on the method is open to discussion.

Implications for nursing

Use of the researchers own lived experience in phenomenology

This paper has suggested that data from the experience of a researcher can be used to both explicate assumptions and

pre-understandings (van Manen 1990) and to access additional data related to lived experience. The question then arises as to how to access this lived experience and to ensure that methodological rigour is maintained. van Manen (1990, p. 30) identifies six research activities, the first two being 'turning to a phenomenon which seriously interests us and investigating experience as we live it'. If personal experience is used as a starting point (van Manen 1990), the researcher is already immersed in the theme (Douglass & Moustakas 1985). Access to these data may be possible by the researcher's writing his/her own story, by keeping a reflective journal or by being interviewed. Reflexivity and use of a reflective diary throughout all stages of research has been well documented (Todres & Wheeler 2001, Patton 2015). van Manen (1990, p. 132) states responsive-reflective writing is the very activity of doing phenomenology.

Alongside the continued use of a reflective diary during the research process, we propose that researchers with experience of the phenomenon under investigation also consider being interviewed. Another member of the research team may conduct this interview, using the same interview guide as for other participants. Ideally, this interview will be conducted at an early stage but the data must not be analysed alone. This process will ensure the same voice/weight is given

to all participants. Besides providing data for analysis, reflection on the researchers' interview can be a bracketing exercise helping to make assumptions explicit. Interviews with participants may then proceed followed by an analysis of the data incorporating the activities described by van Manen (1990) such as reflecting, writing and rewriting, considering the parts and the whole. The researcher and the reader can then determine usability, credibility, trustworthiness and auditability of the research findings.

Interviewing of the researcher can be utilized when the experience of the researcher is to be incorporated into the data and allows for completeness of data collection recognizing multiple realities (Tobin & Begley 2004). The principle described by Patton (2015) of reporting any personal and professional information that may have affected data collection, analysis and interpretation must be adhered to but the researcher may use a pseudonym in publication to ensure that anonymity of their data is maintained along with that of other participants. Possible future areas of nursing research using this approach include investigations of lived experience of any phenomenon which affects the nurse researcher. Examples include medical conditions where the researcher has been diagnosed with the condition, working conditions such as investigations into shift workers or aged care nurses undertaken by shift workers or aged care nurses and cultural research where the researcher belongs to the culture under investigation.

It must be remembered that there is no one correct research method, however, authors such as Crotty and Paley believe in the importance of the interpretation and application of phenomenology as a methodology and method (Crotty 1996, Paley 2000, Barkway 2001, Dowling & Cooney 2012, Petrovskaya 2014b). To ensure credibility in nursing research, the take home message for researchers remains that a thorough understanding of the philosophical underpinnings of the method employed and aligning data collection strategies to those underpinnings is as important as getting clinical practice correct (Petrovskaya 2014b). It must be acknowledged, however, that methods are never perfectly executed as described in textbooks in accordance with the constraints existing in efforts to conduct research (Sandelowski 2010). Participant observation and reflection on participant observation and field experiences while interviewing, which were not the focus of this paper, might, however, also be rich sources of data. There is the expectation that the relevance of the methodology, theoretical framework and methods to the research question are coherent to ensure the premise of transparency, reflexivity and positioning necessary for quality in qualitative research.

Conclusion

This paper has described how data from the researcher could be used to both explicate assumptions and pre-understandings (van Manen 1990) and to generate additional data. Phenomenology is a well-accepted, appropriate research method for exploring phenomena of interest to nurses. Utilizing the experience of the researcher makes use of an important and necessary data source and is well accepted. When the researcher has 'insider' knowledge related to the research question, results can be improved by adding this knowledge to the data. A qualitative approach to research utilizing a heuristic hermeneutic phenomenological method as described, will ensure the appropriateness of including the interview data from the nurse researcher. It is appropriate to include the experience of the researcher provided the methodological considerations of usability, credibility, auditability and trustworthiness and the philosophical choices underpinning the research are coherent and made explicit. This practice ensures rigour in the research and provides truthful, reliable results regarding the phenomenon under investigation. Ultimately, the objective of health research (not just nursing research) should be to improve practice and aid in the provision of better health outcomes for all; ensuring methodological rigour assists in acceptance of qualitative research findings and allows a variety of perspectives to inform healthcare practice and policy development. Other options to engage with the researcher's experience could be explored further.

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- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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THE RESEARCH DESIGN

Although chronic pain is not considered to be a life-threatening condition, it can be a life-long, serious, life-changing condition. van Manen (1990, p.164) noted that “the study of the experience of a chronic life-threatening illness may require the invention of a unique method”. The appropriate research method is determined by the chosen methodology and the research question (van Manen, 1990). For this hermeneutic phenomenological study, a variety of methods of data collection were employed.

“The reason for reflecting on method is to discover the historical approaches and suppositions that may hold promise in rendering human experience interpretable and understandable in our present time and place. So, the expectation is not to arrive at a recipe, a foolproof set of techniques and know-hows that are guaranteed to produce repeatable scientific results; rather, we hope to become sensitive to some of the principles that may guide our inquiry”. (van Manen, 1997, p.346)

The hermeneutic phenomenological activities described by van Manen (1990, pp. 30-1), include turning to a phenomenon which seriously interests us, investigating the experience as we live it, reflecting on the essential themes, describing the phenomenon through the art of writing and rewriting, maintaining a strong orientation to the phenomenon and balancing the research by considering the parts and the whole. These activities align with the heuristic phenomenological analysis activities described by Moustakas (2011): immersion, incubation, illumination, explication and creative synthesis. I have not invented a method but have combined the activities of van Manen and Moustakas to organise six research activities commencing with turning to a phenomenon which seriously interests us, or immersion followed by the first phase of data collection:

1. Lived experience is the starting and end point of phenomenological research (van Manen, 1990). Turning to the nature of lived experience within phenomenology and heuristics requires one to “live” the question or become immersed in it (Moustakas, 2011; van Manen, 1990). The first stage of this research was orientating to the phenomenon. The literature review (refer to Chapter Two) revealed the known understandings of chronic pain and asked the question “where does CRPS fit within these known understandings”? Following this publication, my participation in an interview helped to explicate my assumptions and because of in-depth discussions with my supervisors, determine my subconscious biases with the phenomenon. This is

immersion as described by Douglass and Moustakas (1985); the act of becoming in touch with my own perceptions and awarenesses stemming from my internal frame of reference. This interview also aligned with the concept of using personal experience as a starting point as described by van Manen (1990).

2. Investigating experience as we live it rather than as we conceptualize it involved the first phase of data collection via participant interviews. The experts on living with CRPS, those who suffer from the condition, were interviewed because understanding the essence of the lived experience should be studied from the perspective of those who live it (Schwandt, 2007; van Manen, 1990). In order to determine the meaning this cohort has for their condition, a semi-structured interview was used so that participants could feel empowered to tell the story of their lived experience with chronic pain (Punch, 2009; van Manen, 1990).
3. van Manen (1990) directs researchers to consider other sources as resources for the collection of experiential material such as art and literary sources, including not only poems, novels, stories etc. but also biographies, journals, diaries and logs. To this end, I accessed textual sources from a book and utilised information found on the internet due to it being easily accessible and utilised by people living in many parts of the world. As the internet is such a major source of information for many people it cannot be ignored in the current social climate. As the only language I speak is English, I was restricted to English language sources.
4. Reflecting on the essential themes which characterise the phenomenon involves attempting to describe the lived experience and reflecting on the thematic meanings that were appearing (van Manen, 1990). When exploring the formulated themes in this manner, van Manen identifies four existentials that help to guide hermeneutic reflection in the research process. These are: lived space (spatiality), the way people feel when in the space they find themselves in; lived body (corporeality), the way in which participants revealed or hid aspects of their bodily selves; lived time (temporality), the temporal or time-based way of being in the past, present and future; and lived human relation (relationality or communality), the relationships maintained with others (1990, p.101). These existentials guided both the health practitioner interviews and reflection on the themes. For example, lived time featured in HP interviews when the discussion centred on the delayed diagnosis of participants. When reflecting on lived space, attention was given to experiences of being in

particular spaces as related by the participants, such as the experience of walking in crowded public places.

5. Following the reflection, phase two interviews were conducted with prominent world experts on chronic pain and CRPS regarding the themes I had uncovered. van Manen (1990) calls this a collaborative discussion or hermeneutic conversation, and such discussions can result in greater insights and understandings.
6. A strong and oriented relation to the phenomenon was maintained throughout the final stages of data analysis by performing three of the activities proposed by van Manen (1990). The phenomenological attitude of balancing the research by considering the parts and the whole was adopted, reflecting on themes and writing and re-writing was undertaken while continuously being reflective and reflexive (Crotty, 1996; Patton, 2015; van Manen, 1990).

The data collection activities will be described in further detail next.

DATA COLLECTION VIA PATIENT INTERVIEWS

Recruitment of participants

Purposive sampling was used to recruit participants for this stage. After receiving ethics approval, I contacted the administrators of The Oz RSD Forum, an online support group for people who have been diagnosed with CRPS, and I also contacted Chronic Pain Australia which is a support group working to de-stigmatise pain and provide support, research and awareness for all chronic pain conditions. I joined many Facebook CRPS groups, many of which are private groups. I contacted the administrators of these groups and explained that as I have CRPS I am a legitimate member, but I am also researching the condition and asked for permission to advertise my project. No groups refused my request though some preferred the administrators to post about my project while others asked me to write the post myself.

One Facebook group, CRPS UK, is the online arm of a larger national support group which contacted all their members providing them with information about the project and asking interested people to contact me. Word of mouth and snowballing were also successful strategies to contact potential participants. Friends referred people to me and some people who were interested in being interviewed referred their friends. I sent the RPIS and consent forms to everyone who contacted me. I sent information to more than 50 people and approximately 30 people contacted me to express interest in participating.

The main reasons for non-participation were inability to be interviewed within my timeframe, not being well enough to participate in an interview at the scheduled time and not wanting to disclose and relive their experiences. I stressed to potential participants that they could change their mind at any time, even during the interview without providing a reason. Some interviews were postponed, and some were cancelled due to ill health and any person who was unsure of their ability to tell me their story was advised to not sign a consent. Participants were advised that data would be published in a manner making it extremely difficult for anyone to infer their identity, and they were also told that I too have been diagnosed with the condition and am a participant in the study.

The Interview

Interviewing is considered a useful technique to discover the meaning people make from their experiences, and has gained in popularity and acceptance as a research technique in line with that of qualitative research, especially since the 1970s (Gubrium & Holstein, 2003; Patton, 2015; Seidman, 2013). There are many interview procedures which may be adopted in phenomenological research and I chose to base my approach on Seidman (2013) who utilises the notion of exploring lived experience as described by van Manen (1990) to offer a phenomenological approach to in-depth interviewing suitable for doctoral candidates.

Patton (2015, p. 438) presents four interviewing approaches that are employed in collecting qualitative data:

- The informal conversational interview offers maximum flexibility and most questions flow from the immediate context of the conversation.
- The interview guide approach outlines a list of questions to be explored that might be asked as the interview unfolds as necessary. The guide may be used as a checklist to ensure all relevant topics are covered during interview.
- The standardised open-ended interview consists of the same questions asked of all participants in the same order.
- The closed, fixed response interview contains predetermined questions and responses. The respondent chooses among the fixed responses and their choice is limited.

While each interview necessarily was different, I employed a conversational style and used a guide to ensure participants covered a range of issues. Seidman (2013) identifies four themes that provide structure for the phenomenological interview commencing with the temporal and transitory nature of human experience. In the process of asking participants to tell of their

experience, the phenomenological researcher is requesting participants to reconstruct or search for the essence of that experience. The second theme identified by Seidman (2013) is subjective understanding, the act of striving to understand the experience of the participant from their point of view which necessitates a phenomenological interview approach. The third theme of lived experience as the foundation of phenomena (Seidman, 2013), directed the choice of the opening interview question once demographic data was obtained. Participants were asked to “please tell me your story about living with CRPS”. This question also helped to place the emphasis on meaning and meaning in context which is the fourth theme suggested by Seidman (2013) and helped to ensure each interview was underpinned by phenomenological principles. The existentials of time, space, body and relations (van Manen, 1990) were not directly asked as questions so that participants could organically relate stories from their lifeworld. Thus information regarding these categories was freely prioritised by the participants.

Pilot interviews were conducted to ensure the interview structure was appropriate and to ascertain the interview technique would support the objectives of information gathering to answer the research question (Seidman, 2013). Participants were interviewed face to face, on Skype or by Skype telephone depending on their location and preference. When I had some opportunity to travel within Australia, some of the participants living interstate were interviewed face to face. The 17 interviews lasted from 34 to 92 minutes (*average = 51 minutes*).

Prompts were used to generate further discussion on points participants had not covered in the telling of their stories. There were two levels of prompts. Level 1 prompts were asked to gather more information about an incident. Examples of prompts used in this instance were “tell me more about the financial implications of altering your house” and “can you give me an example of those changes you made to cope with the physical limitations?” Level two prompts were used when the meaning required further exploration. An example of a level two prompt used is “how did that make you feel?”

Care of participants

Following consent, the participants nominated their preferred date and time for the interview and although offered the option of having a support person present, no one chose that option. Due to previous employment, I have experience dealing (on the telephone) with distressed and crying people and wanted the interview to be as easy as possible for participants. Therefore, I asked them to tell me if they wanted to pause or stop the interview for any reason

and gave examples such as needing a toilet break, getting tired or someone in the house overhearing them, and had tissues on hand for all face-to-face interviews. Participants' family members occasionally came into the room briefly during the interview and one interview was paused due to this at the request of the participant.

Some participants became emotional during the interview and on each occasion, I offered to turn the tape off in accordance with the ethics application, such as during the following interview:

I was seeing a really good psychologist locally, fantastic and I was really looking at feelings of grief where I had this belief at this stage where I would never stop feeling the grief... Crying.

I'm so sorry it's not my intention to upset you. Do you want me to stop the tape?

No. no it's ok. It's fine because it's like all my emotions. I'm a much stronger person because of this but all those heart felt emotions, they're always sort of simmering under the surface. Rosemary

Debriefing was performed following the interviews after the tape was turned off as a strategy to help leave the participants feeling empowered about the experience.

DATA FROM THE RESEARCHERS' OWN EXPERIENCE

Following pilot interviews, I was interviewed for this research by one of my supervisors – Dr. Florin Opreescu. This interview served multiple purposes. It allowed for explication of my pre-understandings and assumptions and provided another source of data. To ensure transparency of my voice throughout the research process, I did not choose a pseudonym. This strategy safeguarded against unintentional bias in the analysis, aiding my supervisors to see things from my perspective and follow the decision trail.

Once all of my supervisors had read through my transcript, it was acknowledged that my beliefs were not evident in the transcript (See Chapter 1 Introduction, Explication of pre-understandings and assumptions). Additionally, sub-consciously, I had the following biases which surfaced through a discussion of my transcript:

- a) CRPS is an awful thing to live with;
- b) Support does not necessarily come where you expect it to;
- c) Health professionals are not always good at treating CRPS; and

- d) Only people living with CRPS truly understand what it's like.

Furthermore, I had the following beliefs about myself as a person with CRPS which must also be acknowledged:

- a) I had an initial fear of living with CRPS;
- b) I experienced a loss of confidence in myself and my coping skills
- c) I felt I couldn't trust my body;
- d) I had difficulty accepting my changing limitations; and
- e) I believe there is value in learning about the condition.

TRANSCRIPTION

I decided to transcribe the pilot interviews myself. My diary at the time reminds me that this was an extremely time-consuming task which I found to be mentally and physically demanding. These demands were something I hadn't expected. It was difficult to not get caught up in the story, but I became extremely familiar with the data in these transcripts through the process of transcribing the interviews myself (Patton, 2015).

Following my interview with Dr Florin Oprescu, I found it too difficult to transcribe it myself. My hand ached every time I started to transcribe. I also had the same difficulty transcribing the next interview. Moustakas (2011) expects that the researcher should be affected by the interview and believes that the participant and interviewer relate to one another best when they are "both caught up in the phenomenon being discussed" (p. 11). I decided to pay for transcription services for most of the other interviews. This allowed me to interact with the data without it consuming me. I found I had to read and re-read these transcripts and listen to tapes again to gain the same level of familiarity with the data I had with those I had transcribed myself. In doing so, I maintained rigour at the same standard for all transcripts.

DATA COLLECTION VIA HEALTH PRACTITIONER INTERVIEWS

Health practitioners (HPs) while not experiencing the phenomenon themselves are part of the life context of patients with CRPS. HPs who attended the IASP Special Interest Group in CRPS Conference in Cork, Ireland, 2017, were spoken to regarding participating in interviews related to the poster I had on display. Those HPs who showed interest in the work were handed or emailed the Research Participant Information Sheet (RPIS) and Consent forms. Although more

people signed consents, four HPs were interviewed by Skype or Skype telephone at a time and date of their choosing. The interviews lasted between 35 and 48 minutes (*average = 42.25 minutes*). The CRPS research community is quite small and a total of 240 people attended the conference where these HPs were recruited. These participants are considered leading world experts in CRPS and as such, they are potentially easily identifiable. Therefore, demographic information was collected so that participant (and non-participant) anonymity could be maintained.

My purpose in interviewing the health professionals was to gain greater understanding and increased depth of meaning of living with CRPS through discussion of the emerging themes from the patient interviews. van Manen (1990) states that hermeneutic discussions on themes and thematic descriptions of phenomenon, such as those conducted with the health professionals, generate deeper insights and allow the author to identify and transcend the limits of their present vision. Health professionals, while not experiencing the phenomenon themselves, interact with patients and play such a large part in the lives of patients, that their perception can influence the course of the health/illness trajectory for patients and influence policy and procedures regarding managing the patient with chronic pain. Therefore, the research question was: What are the perceptions of HPs regarding the themes generated by the patient interviews? A transcription service was used for all four interviews. As with the patient interviews, these transcripts were read many times to gain deep familiarity with the data. Interviews were conducted, and transcripts were analysed by following the same methods as with the patient interviews.

ETHICAL CONSIDERATIONS

Ethical standards in Australia are based on the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research. Throughout the past 60 years, the values of respect, research merit and integrity, justice and beneficence have provided the principles and guidelines for the conduct of research (NHMRC, 2016). These values will now be discussed.

Respect

Before gaining ethics approval, there were several procedures to follow commencing with an assessment of risk which may be financial, physical, social or psychological. In this research the potential existed for some people to become upset during the interview or remain despondent

following its completion. To minimise this psychological risk the following strategies were in place:

- Facial tissues were available for face to face interviews;
- Any participant who became upset or seemed to be becoming upset was offered the chance to pause or stop the tape and/or interview;
- Participants were reminded that they could stop the interview at any time without giving a reason;
- Silence was encouraged if a participant required time to collect their thoughts;
- The last interview questions were framed to focus on positive experiences and debriefing was performed at the completion of each interview, so participants were more likely to feel empowered about the interview experience; and
- Contact numbers for psychological support were available along with details of supportive websites if needed. Participants would have been referred also to their GP, pain management specialist or other health professional if they had been upset at the end of the interview. Each participant was asked to contact me if they felt they wanted to discuss the interview further, but no one did this.

Research merit and integrity

The design of this study was peer reviewed and judged to reflect the value of research merit and integrity. The potential benefit as described by NHMRC (2016) is the contribution to knowledge and understanding of living with chronic pain, particularly CRPS. It was based on current literature describing living with a chronic pain condition and developed using methods like those published studies. Publications will not reveal potentially identifiable details about the participants. Health professional participants are known by a number and little demographic information will be published so that those who chose to participate will remain anonymous. Integrity is demonstrated by the commitment of all researchers and supervisors conducting the research honestly and following all recognised principles of research conduct.

Justice

Justice considers the selection of participants and includes fairness in recruitment. Each person who expressed interest in the study was sent the information sheet and given ample time to ask questions. Inclusion criteria for this research were ability to provide informed consent and ability to converse in English. There were no initial exclusion criteria. After one pilot interview participant admitted self-diagnosis, the inclusion criteria were amended to ensure all

participants had been formally diagnosed with CRPS by a medical specialist. Pilot interviews of participants meeting the inclusion criteria were included in the analysis. Interviews were conducted at a time and place of the participants choosing and interviews were postponed or cancelled at their request. Findings have been disseminated to participants as appropriate.

Beneficence

The Research Project Information Sheet clearly stated that participants will not receive any direct benefits for participating but that by providing information, health professionals can be better informed which may lead to an improvement of health services available.

Ethics approval

The research was deemed to be suitable for a Low Risk Ethics Application form submission and was approved by University of the Sunshine Coast Human Research Ethics Committee number S13577 from 28/03/2014 until 28/03/2019. (Refer to Appendix A). Annual Reports were submitted each year in March. Copies of the Research Project Information Sheets (RPIS) and Consent Forms are available in Appendix A. (Refer to Appendix A). After being accepted for a poster at the International Association for the Study of Pain (IASP) Special Interest Group on CRPS conference in Cork, Ireland, I submitted an addendum to my ethics application so that I could interview health practitioner attendees. (Refer to Appendix B for the ethics approval and health practitioner RPIS and consent forms).

DATA ANALYSIS

van Manen (1990) provides a guide to assist the researcher to develop themes but first gives a description of a theme. He believes a theme is “the sense we are able to make of something” (p. 88) and it describes the essence of the notion we are trying to understand. The explication of themes is the means by which the essential structure or form of lived experience is delivered and provide the framework on which to build the story of the phenomenon so that it makes us think, feel and reflectively recognise the lived experience of the phenomenon (van Manen, 1997). Once transcript themes have been identified, these themes may become objects of reflection in follow-up hermeneutic conversations in which both the researcher and the interviewee collaborate (van Manen, 1990). In other words, both the interviewer and the interviewee attempt to interpret the significance of the preliminary themes in the light of the original phenomenological question. Both the researcher and the interviewee weigh the appropriateness of each theme by asking: “Is this what the experience is really like?” (van

Manen, 2011). The latter participant interviews and HP interviews included a discussion on themes in this manner.

There are three approaches proposed by van Manen (1990, p. 93) to uncover thematic aspects of a text, and all three were utilised in this research.

- I. The wholistic or sententious approach involves identifying a phrase or statement which conveys the meaning of the entire text and formulating a phrase to articulate that meaning.
- II. The selective reading approach involves highlighting the phrases or statements which are fundamental, or especially revealing about the phenomenon.
- III. The detailed approach involves close reading of the text and asking questions of every line, sentence of a paragraph.

Heuristics and hermeneutical phenomenology share a commonality in approaches to analysing data. Moustakas (2011) directs the researcher to immerse themselves in the data, take a rest and then return to the data again to gain intimate knowledge of the material. Similarly, the hermeneutic circle may be taken to mean moving back and forth between excerpts of data (Crotty, 1996) or studying the whole and the parts, that is looking at sections of text and then looking at the text as a whole (Patton, 2015) which necessarily requires one to take a break and then look again with fresh eyes.

As phenomenology is the art of writing and rewriting (van Manen, 1990), many lists were compiled and turned into meaning statements and paragraphs in an attempt to analyse the data and devise meaningful themes. The order in which each interview was analysed was continuously changed so that no one interview was the sentinel interview for coding terms or organisation of thoughts (Wilkinson & Kitzinger, 2013). The main ideas from each interview were each articulated in a sentence. One strategy which was particularly helpful in defining emerging themes involved establishing a word document with headings. After colour coding each transcript and highlighting sections of text, those sections were divided into categories such as guilt, loss, coping, etc. These strategies allowed visualisation of the data in many ways so that the common elements or meaning statements that had been devised could be identified. The process then involved combining the like and separating the different elements. Questions were continually asked during analysis. Examples include:

- What is this person really trying to say?

- What are they alluding to when they talk about xyz? (For example, seeing the health professional?)
- How is this account of an experience (such as coping or not coping), different or the same as the account of it in the previous interview?
- How has this phenomenon been experienced in terms of time, space, body and human relations?

The interview transcripts were read and reread, while asking the above questions and with my aforementioned beliefs, assumptions and biases forefront in my mind. I began to write more detailed accounts of what it is like to live with chronic pain. At this point, I consulted books about chronic pain and CRPS, particularly the book by psychologist Rodham (2015) containing ten patient stories. I also looked to the internet at sites about chronic pain and CRPS or blogs written by people with CRPS to ensure my answers were cognisant with the ideas presented to me by the interviews.

Textual Material

It is likely that reflective descriptions of lived experiences that are of phenomenological value may be found in diaries, logs, and personal life stories (van Manen, 1990). The internet has emerged as a valuable resource for people with CRPS to tell their story to people who have insight and understanding of living with CRPS (Rodham et al., 2009), making it an important source of data for this study. Open internet sites were accessed and the accounts of peoples' experience living with CRPS were read while asking the questions above.

Written accounts rarely contained the depth of information found in the interview transcripts, but five internet sites were examined in depth using the three reading approaches of the wholistic, the selective and the detailed approach (van Manen, 1990) as previously described to isolate thematic statements. The five sites used in the research were the first five sites discovered upon seeking blogs about living with CRPS. A poem was posted on a Facebook site verbalising the emotions of the author. I asked for and received permission to use the poem and share it in the context of this research. Finally the 10 patients' stories contained in the book "Learning to cope with CRPS/RSD: putting life first and pain second" (Rodham, 2015) were read in the same manner as the internet sites and poem. This strategy was helpful in determining the essential themes and distinguishing them from the incidental themes (van Manen, 1990), thus completing part of the hermeneutic circle.

Trustworthiness

Competence and integrity in research are demonstrated by rigour (Tobin & Begley, 2004). Although there has been debate regarding the concept of rigour within qualitative research, the hermeneutic circle is regarded as a traditional process to exercise rigour within phenomenology (Crotty, 1996). Trustworthiness, the overall concept of rigour, can be divided into four parts (Letts et al., 2007): credibility, transferability, dependability and confirmability. Guba and Lincoln (1989) assert these terms are intended to parallel the rigour criteria of internal validity, external validity, reliability and objectivity from the positivist paradigm. I followed the overall guidelines as proposed by Guba and Lincoln (1989) and Letts et al. (2007) and also engaged with the hermeneutic circle (Crotty, 1996). My answers to questions and interview statements were written and re-written and then combined so that I could consider the whole as well as the parts (van Manen, 1990). I collected data over a long period of time from as wide a range of participants as possible. I kept a reflective diary and an audit trail, used various data sources and discussed my ideas and interpretation of data with my supervisors regularly. Following the battle epiphany, I returned to my reflective journal and saw that I had written about struggling, fighting and battling many times. Upon watching videos on YouTube about living with CRPS and consulting internet sites such as CRPS: A Patient's Perspective, I saw that many patients described the same accounts of experience in their narratives.

By looking at further written accounts, the themes previously identified were verified and once no new themes emerged no further interviews were scheduled. It would be impossible however to assert that all the meaning or meaningfulness of the experiences related by the participants was captured because in phenomenology, there is no saturation point (van Manen, Higgins & van der Riet, 2016). The parts – each interview, written account, video blog etc., told a story of trying to live with a difficult diagnosis. The whole – amalgamation of all sources, pointed to people with CRPS battling to live their lives. The phenomenon was examined again to determine which were essential and incidental themes using the process of free imaginative variation described by van Manen (1990) by asking the question proposed by Crotty (1996, p.171), “*would the phenomenon still be this phenomenon if this feature were absent*”? Thus by imagining the change or deletion of a theme from the phenomenon, if the fundamental meaning of the phenomenon is lost, it is an essential theme (van Manen, 1990). By documenting the decision-making process at each step, an audit trail was developed which shows the initial ideas being refined to become themes and sub-themes. The concept of maintaining rigour was further discussed in the publication, *Methodological considerations related to nurse researchers using their own experience of a phenomenon within*

phenomenology (Johnston et al., 2017), which was included earlier in this chapter (Refer to Chapter 3, Publication).

CHAPTER SUMMARY

The previous chapter discussed qualitative literature related to living with chronic pain and CRPS. This chapter has described the theoretical assumptions and underpinnings of the study and the process of gaining ethics approval, consenting then interviewing 17 patient participants and four health professionals for this research. The phenomenological approach to analysis and identification of essential themes has been detailed. The steps taken to ensure rigour were outlined. The publication attached to this chapter further discusses using data from the researchers' own experience to explicate assumptions and preunderstandings and provided an extensive account of maintaining rigour in qualitative research. The following chapter will provide the findings of this research.

CHAPTER 4: FINDINGS

The research question underpinning this study was: *What is the experience of living with chronic pain in the lifeworld of complex regional pain syndrome?* In this chapter, a description of all the data sources will be provided. In addition, the findings from data collected from the conversational style interviews with patients and health practitioners will be presented along with textual data collected online and from a book so that different aspects of the lifeworld of CRPS can be explored.

DESCRIPTION OF DATA SOURCES

Seventeen people living with CRPS and four health practitioners were interviewed. The patient participants will be described first, followed by the health practitioners and the textual data sources.

Patient Participants

Interviews conducted with 17 people living with CRPS were included in this study. As evidenced in Table 2, 14 women and three men participated in the patient interviews, and their ages ranged from 22 to 65 years. Eight participants had CRPS in a lower limb, eight in an upper limb and one person had it in both upper and lower limbs. There were eight Australians, six participants from England and one each from Wales, USA and Singapore. Within the patient participants, formal diagnosis of CRPS was either made or confirmed by a doctor specialising in either pain medicine, orthopaedics or rheumatology. Provisional diagnosis of CRPS was most often made by a physiotherapist or a doctor such as a GP, and every participant apart from Dianne had seen at least one pain medicine physician at the time of interview. The time to formal diagnosis ranged from three weeks to nine years. CRPS was suggested to Martin as a diagnosis at five months, but his formal diagnosis came at 18 months as shown in Table 2. Sharon was tentatively diagnosed with CRPS at four months, but she was not formally diagnosed for three years and this has had a major impact on her level of pain, disability and spread. Patient participants had experienced symptoms from four months to 18 years, as shown in Figure 1. Figure 1 depicts the participants lived time with CRPS. It shows the time to diagnosis and overall length of time each participant had had their symptoms, at the time of interview. Vignettes have been provided in Appendix C to provide the reader with a deeper understanding of each patient participant (Refer to Appendix C).

Table 2. Patient participant description

Chosen name	Age	Time with CRPS	Time to diagnosis	Highest education completed or working towards	Affected body part	Living with at time of interview
Karen	55	7 years	3 years	Diploma	Foot	Husband, daughter (17)
Laura	29	15 years	9 years	Degree	Leg	Parents
Rosemary	64	8 years	5 years	Diploma	Foot	Husband
Colleen	48	4.5 years	3 weeks	PhD	Hand	3 sons (17, 15, 13)
Sharon	46	5 years	4months (3 years formal)	Year 12	Hand	1 son (18)
Fred	41	11 years	2½ years	Year 8	Arm	Wife and 4 children (9-19)
Martin	32	5 years	5 months (18 months formal)	A Levels Apprenticeship	Foot	Wife, baby (8 months)
Emma	45	1 years	3-4 weeks	Masters	Hand	Self
Jackie	55	4 months	3 months	High School	Hand	Mother
Hannah	22	8 years	2 years	Degree	Hand	Friend
Alice	30	5 years	9 months	TAFE Cert 3	Leg	Parents
Dianne	50	4.5 years	3 years	Masters	Shoulder	Husband
Jasmine	25	13 years	12 months	Masters	Ankle	Fiancé
Sarah	45	16 months	13 months	Post graduate certificate	Knee	Husband
Mel	41	9 years	4.5 years	TAFE Cert 3	Shoulder	1 son (18)
Carolyn	65	18 years	Nearly 3 years	A Levels	Arm then Leg	Husband
Paul	58	8 years	2.5 years	O levels A Levels Trade certificate	Leg	Self

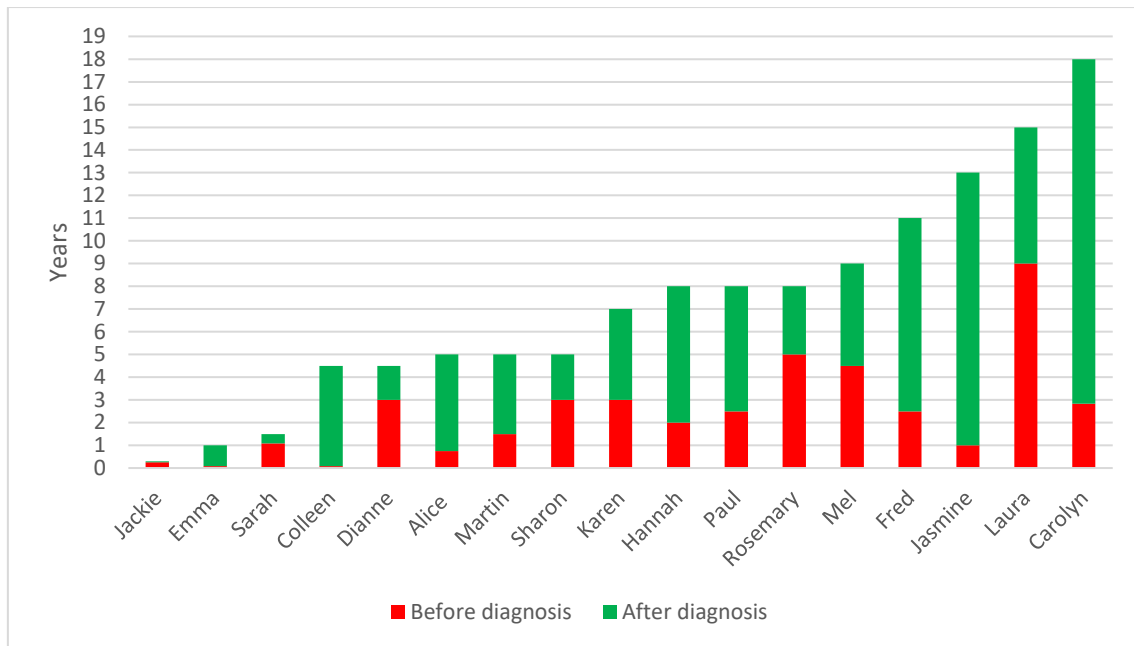


Figure 1. Graph of time living with CRPS pre and post diagnosis

Health practitioner participants

Four interviews were conducted with health practitioners. (See Chapter 3, Data collection via health practitioner interviews for further information). Demographics collected from the HPs can be seen in Table 3. They resided and worked in three countries and had worked with CRPS patients for an average of 23.5 years. Vignettes are not provided for these participants as they are too easily identified if further information is provided.

Table 3. Health Practitioner Demographics

	HP1	HP2	HP3	HP4
Gender	Male	Female	Female	Male
Position Clinician or Researcher	Researcher (former clinician)	Both – transitioning from clinical role	Both	Both
Years working with CRPS (approx.)	25	27	20	22
1st heard of CRPS	Journal club as a clinician	University – initial degree	At work through clinical supervisor	University – initial degree

Textual data

As discussed in Chapter 3 textual data were used to provide parts of the hermeneutic circle and provide evidence for the emergent themes. (Refer to Chapter 3, Data analysis, Textual material for further information). Data sources for textual data were:

- Burning Nights - <https://www.burningnightscrps.org/ourstory/our-founder/> (Victoria);
- Princess in the tower - <http://princessinthetower.org/> (Princess);
- The invisible warrior - <https://theinvisiblewarrior.com/about/> (Kelly);
- Ship with no sails - <http://www.shipwithnosails.com/about-me/my-story/> (Genevieve);
- Hope for Jessica - <http://hopeforjessica.blogspot.com.au/> (Jessica); and
- “Learning to Cope With CRPS/RSD: Putting Life First and Pain Second” by Karen Rodham (2015).

The websites are open internet sites of first-hand accounts of experiences living with CRPS. Although very much shorter than the interview transcripts, each blog relates the battle faced since CRPS symptoms first started for each of the authors. Chapter 2 of the book is titled “What is it like to live with CRPS?”. This chapter contains stories from ten people written by Professor Rodham, an English chartered health psychologist specialising in CRPS. She has used direct quotes from the people themselves and provided a narrative to tell each story. A poem posted on Facebook was another source of data. It is reprinted in full at the end of this chapter.

THE EMERGENCE OF THE MAJOR THEME

Following the reading and re-reading of the sources of data a number of minor themes had started to emerge. A major turning point in the analysis occurred when reading the account on the site theinvisiblewarrior.com and considering the names of many CRPS support groups. The words ‘warrior’ and ‘fight’ occurred again and again. This resonated with every other minor theme I had identified. As Kelly said,

“I fight. I fight because I am terrified if I quit that I won’t get up again. I fight because I can’t imagine a life that I am confined to a wheelchair. I fight because there are also others who are fighting their own battles that are greater than my own”. (Kelly)

This prompted further re-reading of the interview transcripts. Another word that was used extensively was battle. Engagement with the transcripts and the thematic analysis derived that the essence of living with CRPS is a constant battle. This is like many other chronic conditions and cancer where sufferers often describe themselves as battling their condition. The quote

from Kelly prompted the realisation that this was the essence of the phenomenon and was mentioned throughout the transcripts. Every person interviewed had described a constant daily fight or battle and many people on the open and closed internet sites referred to themselves as warriors fighting the condition. Following this realisation, understanding of this concept and development of the themes was found to be supported in the blogs, the book, and in the interviews with the health professionals. Following hermeneutic reflection on the patient interview data (as described in Chapter 3 Methodology and Methods), five themes emerged. Within a battle, there are many fights, each involving multiple combatants. These many fights make up the themes which are presented in this chapter.

LIVING WITH CRPS IS A BATTLE

Living with CRPS is a battle. CRPS is the enemy and the patients are the warriors or soldiers fighting it. The lifeworld of CRPS is different for patients and health professionals who live and experience separate aspects of the disease. This research involved the exploration and analysis of data from patients to develop the thematic structure of the writing and each theme will be presented as distinct yet enmeshed with the others. An understanding of each theme was built through a reflective process which included data from all of the sources so that an exploration occurred of the various aspects of the lifeworld from different perspectives. Five themes were identified and in keeping with the battle analogy, they were named as follows:

1. Dealing with an unknown enemy;
2. Building an armoury against a moving target;
3. Battles within the war;
4. Developing battle plans with allies; and
5. Warrior or prisoner of war?

These themes will now be discussed in greater detail.

DEALING WITH AN UNKNOWN ENEMY

An enemy is a person who hates or opposes another person and tries to harm that person (Cambridge, 2018). In the context of this thesis, the enemy is complex regional pain syndrome. This theme incorporates the unknown aspects of CRPS. According to HP1:

It definitely is an unknown enemy because not even the people who are providing CRPS care really understand firmly what causes it. HP1

Sub-themes are:

- CRPS is a rare and largely unknown condition;
- Multiple terms are still used for the condition;
- Poor health literacy of patients;
- Receiving and acting on poor advice; and
- Psychological response to development of symptoms.

CRPS is a rare and largely unknown condition

Prior to diagnosis, many patients know there is 'something wrong' but are often not believed.

Diagnosis was a long process for most participants:

We spent about four years bouncing between physios, him telling me that I was um, hypochondriac, hysterical teenager, it was all in my head. Laura

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

Participants described going on a "quest" for a diagnosis as Rosemary called it, consulting many health professionals and receiving multiple incorrect diagnoses resulting in inappropriate treatment:

And the physiotherapist said, "Oh well it's a nerve problem, we need to do some nerve stretching". And he gave me another series of exercises to do and the pain just got worse and worse, to the point where I was in tears. I've never felt pain like it and he was very unsupportive, almost as though he really didn't believe the level of pain that I was in." Dianne

The CRPS diagnosis was first suggested by a physiotherapist for most of the patients interviewed. However, each participant saw a variety of health professionals including the GP, sports doctor, specialist paediatric centre and pain management specialist for a formal diagnosis:

I think you just get to the stage where it's like, I can't help you, and you just need to go away. So, they just keep writing you a piece of paper to see someone else. I don't care who it is you know, here's a piece of paper to see the cleaner. (Laugh) You know; we've run out of options. And then you get to the last person and they want to start you again. So eventually I got to see a hand specialist. Sharon

It is even less known in the general community which impacts the understanding and support given to patients:

And I wish I had something which was a bit more common, because people find it really difficult to understand what the condition is, even if you explain it to them. Sarah

Despite attempts to blend in with their surroundings, patients faced difficulties. Carolyn only has the use of one arm. She related a story about being in a restaurant and getting the chef to cut her meal up before serving it. The people at the next table commented loudly “How uncouth, why on Earth is she only using one fork? That’s disgraceful”! Carolyn

Multiple terms for the condition

Once patients receive a correct diagnosis and gain some understanding of their condition, they still face the problem of living with a little-known condition:

It was called algodystrophy originally. And nobody knew, because we lived quite rural, nobody knew, and they still don’t know CRPS in my local hospital. Carolyn

To complicate matters, the outdated term Reflex Sympathetic Dystrophy (RSD) is still used in some quarters (particularly USA) making the term CRPS even less recognisable. One of the largest support groups in USA (and indeed in the world) is called Reflex Sympathetic Dystrophy Syndrome Association, or RSDSA. Their Summer 2017 community update spoke about the various name changes of the condition:

How do you say CRPS? Do you say CRPS? Or RSD? Or CRPS/RSD? Or RSD/CRPS? Any way you say it: pain by any other name is...PAIN. (Wordgirl, 2017)

Health practitioner interviews revealed that the executive committee of the RSDSA have discussed changing the name but believe they have a branding issue:

They are very successful fundraisers and their concern is that by changing the acronym then they would lose some of their funding and identity. HP3

I am on the RSDSA scientific advisory committee and I have mentioned that to them before and I think that they just feel like they have to maintain continuity as an organisation by keeping the same name. (...) it is much better to have one term that everybody uses. Because even now twenty-five years later, there are clinicians out there who still call it RSD. I, sometimes in talking with physician, I say CRPS and they just kind of look at me, then I say you know Reflex Sympathetic Dystrophy, and they are just like oh yeah ok. HP1

Poor health literacy of patients

Many patients have poor health literacy and therefore do not understand medical terms. The health professionals interviewed described varying techniques to address this issue ranging

from patient education about pain neurophysiology to providing fact sheets and lists of reputable websites:

As health care professionals our duty is to produce the results of our research into patient accessible information and to make that widely available ... There aren't that many internet sites of CRPS that do have reputable and useful information. HP3

Some patients do not want to access information and are afraid to face what might be ahead of them. As a child, Jasmine tried to ignore her condition:

Like I never really bothered to research CRPS because frankly it scared me. Like I had this ticking time bomb in my body that I didn't really want to know a whole lot about, so I didn't research it. Jasmine

Receiving and acting on poor advice

Once diagnosed, participants often received poor information from health practitioners:

*The OT at this private hospital said, "oh you've got CRPS Colleen and that's crap (...)
just forget about it and it will get better". Colleen*

So, we went to the GP and asked him what we need to do (to get a referral to a specialist CRPS pain centre). He wasn't sure. Saw the orthopaedic doctor again and he wasn't sure. Martin

But when we saw the doctors they didn't really know what to do with me. And apparently at that point they said I was too young for medication. Hannah

Unless they are health professionals themselves, patients have minimal access to peer reviewed research, and find this literature hard to understand; therefore, they look to other sources, namely, the internet and each other for information, guidance and support. The information they receive is not necessarily correct and can be quite dangerous:

She was nuts, this Kate, she would ask people with RSD/CRPS to do painful things to their affected area/limb like rub sandpaper on it to bring on remission and she'd ask them to video them crying and screaming and send it to her. Tracey (Facebook)

Psychological response to development of symptoms

When people first experience CRPS symptoms, they are confused because the injury should have healed and should not be as painful as it is. There is a psychological response that most people experience:

(...) I lost so much confidence in myself. I was having panic attacks, which I didn't recognise as panic attacks. I had this pain that just would not stop, and honestly, I felt like I was going mad. I just couldn't trust myself, couldn't trust my body. Colleen

I seem to be more emotional than ever because of the CRPS. I cry so easily ... I'm crying at the drop of a hat. Is it the gabapentin, is it the CRPS or is it a combination of 4 or 5 things? I sometimes have a cry and get emotional because I want my hand back, I was very active. Jackie

BUILDING AN ARMOURY AGAINST A MOVING TARGET

An armoury is usually taken to mean military equipment or weapons, or their place of storage but it can also mean things or qualities that can be used to achieve a particular aim. In the context of this research, the armoury is everything a patient does to improve their health. CRPS is defined here as a moving target due to the changeable nature of the condition. What is possible for a patient one day is not necessarily possible the next day. CRPS is not a stable disease for many patients, however some experience mild symptoms and achieve remission (or at least effective management of pain and other symptoms) but may experience a flare following further injury, illness etc., or their condition may deteriorate spontaneously, seemingly without a cause. Patients live with the knowledge that their condition may improve but may also worsen.

Building an armoury against a moving target begins once patients have been diagnosed and begin to form a plan to live with the condition whilst being or becoming aware of the reality that CRPS changes over time. Spread plays a part here, with the disease taking up a larger part of the body. Patients with 'stable' CRPS can experience flares following surgery, illness and tiredness, or anything that puts the person under stress. Management of flares may require higher doses or a change to a patient's medication regime. People often have to weigh up the choices – stronger pain killers will stop the pain, but the patient then can't drive and get the kids from school or increased medication may result in other effects such as worsening constipation. Unfortunately, in some cases medications stop working, or the side effects get too much, and patients have to find alternatives. Therefore, within this theme, sub-themes are:

- The unknown aetiology;
- No dedicated medication or treatment;
- Medications can cease to have an effect;
- The balance between quality of life and side effects of medication;
- Exploring treatment options; and
- Spread and fear of spread.

The unknown aetiology

The aetiology of CRPS is still largely unknown which makes it difficult to find effective treatments compared to treating more common types of pain. This makes the condition difficult to live with but captures the interest of researchers:

There are definitely differences compared to many other chronic pain conditions. My own opinion of that is that some of the differences are how dramatic the symptoms are, and I think that has an effect on the patients. Where it is much harder to just go on with your life and do your best to act like you don't have anything at all. Because you have got the dramatic swelling, the colour changes, temperature changes. My experience is that the hypersensitivity in CRPS is greater than you see with many other pain conditions. Which I think interferes with functioning for many patients, more than other chronic pain conditions. So, there are some differences. It is not totally different. There is a lot of overlap too. HP1

I: So those differences, does that make it more complicated as a researcher?

It doesn't make it more difficult; it makes it more interesting. There is more that I think is unknown in CRPS than many other conditions. HP1

No dedicated medication or treatment

Initial treatment usually consists of oral medication and physical therapy. As there is no dedicated treatment, many patients find themselves accessing a large number of health practitioners for treatment and being prescribed copious amounts of medication. Table 4 lists some of the treatments and medications the interview participants mentioned. This list is not exhaustive, as direct questions about amount of medications taken and treatments undergone were not asked. The table gives the reader an appreciation of the amount of health-related appointments and treatments the participants mentioned in their interviews (Refer to Table 4):

Once I was diagnosed I tried all the different things, physio, medications, hydrotherapy, the small stuff that you try first before try things like nerve blocks and all the bigger stuff. So, I did all that. Alice

I had a lumbar sympathetic block, where they tried to just, I guess, cut off all the feeling to my leg, for a little while. And that really didn't work. (...) When I was thirteen they did this thing called a Capsaicin Burn (...) it was excruciating. Jasmine.

And basically, I'm tied to medication. I take thirty-two tablets a day with my pain relief (...) And I'm on some very, very powerful stuff. You know Tramadol the maximum dose, Gabapentin the maximum dose. Duloxetine and Amitriptyline. Oh yeah there's Lovastatin as well to keep things ticking along you know. {Laugh} Still it's a big cocktail of drugs to take every day and if I don't take my meds then I find that I just sort of seize up, and then I cannot do anything. Paul

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Table 4. Treatments and medications tried by participants

Treatment or medication	Rosemary	Karen	Jasmine	Colleen	Sharon	Laura	Dianne	Carolyn	Alice	Emma	Paul	Hannah	Sarah	Martin	Fred	Mel	Jackie
Surgery	XXX	XX	X	X		XXX				XX	X		XX		X		X
Pain program	X			X	X		X	X			X		X	X		X	
Mirror therapy				X	X												
GMI*						X											
Mindfulness				X		X	X			X							
Distraction												X					
Meditation					X	X	X			X							X
Hydrotherapy					X				X		X						
Alt therapies*				XX	XX											XX	XXX
Lyrica/Gabapentin		X		X	X		X	X		X		X	X	X	X		X
Endone/Tramadol			X	X	X			X			X			X	X	X	
Opiates		XX	X	X	X	X						X	X		X	X	
Antidepressants		X		X	X	X					X	X	X	X	X	X	X
Nerve block	XXX	X			X			X	X	X				XXX		X	

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LS Block*	X		X			X											
SC Stimulation*	X		X			X			X								
Ketamine	X		X		X												
Capsaicin			X														
Botox	X					XX											

* GMI - Graded motor imagery; Alternative therapies such as kinesiology, acupuncture, osteopathy, naturopathy which may include medication;

LS Block - Lumbar sympathetic block; SC stimulation – Spinal Cord Stimulation. X indicates the number of treatments or medications.

Medications can cease to have an effect

Medication regimes may require change for many reasons including tolerance to the medication, illness or stress which often results in higher doses being prescribed.

Unfortunately, in some cases medications can cease to have an effect and patients must find alternatives:

And the first two Ketamine infusions were very effective. (...) But then they tried more of them, I think I've had five sets total. And the last couple of sets didn't seem to do anything.
Jasmine

Sometimes, the spread is too extensive and there is no alternative medication:

Within the first year it spread to both my legs and both my hips. For me it spread then to my spine and then around the third year it spread to both my arms and both my hands and they had to remove a whole bunch of my teeth, so it spread into my mouth, because my teeth were falling out because of the CRPS. It spread to my lungs and just recently has spread to my stomach and my digestive system. So, I have struggles eating and keeping food down and things like that sometimes. Alice

The balance between quality of life and side effects of medication

Finding the balance between medication side effects and quality of life was an issue for many of the participants. Females were especially concerned with weight gain once commencing Lyrica, with gains from 15 to 27 kilograms in the patient interview cohort. This impacted heavily on their self-confidence and identity as, being unable to exercise, the weight increased further, in one case between 40 and 50 kg. Difficulty thinking clearly or “brain fog” was another major side effect experienced and participants attributed this to medication (particularly Lyrica) and CRPS itself. They described how it worsened if they were tired, labelling themselves as “spaced out”:

My wife always fills in the blanks because I forget things quite frequently. Martin

He said, “just take one Lyrica at night and they might make you feel a bit spacey”. And he was right. Like the next morning I was like “Oh my God – what on Earth did he give me”? Anyway, I took them for about three weeks. (...) he upped the dose to two a day. But I just couldn't function. Emma

It takes the pain away, it also takes your thoughts away sometimes. Paul

Lack of concentration not only affected participants' abilities to work or study, but also to participate in everyday conversations. Forgetting words or being unable to follow a

conversation was particularly confronting and some chose to isolate themselves as it was “too hard”. Others worry about how they are perceived by others:

But this is something else that affects me quite deeply; it's the brain fog which is quite difficult. Because when you're talking to someone, I would consider myself fairly intelligent, but it doesn't always come across in conversation, because it's generally quite broken. Hannah

Forgetfulness and memory loss impacted medication too as some people forgot to take it. The most common strategy to deal with this was to have an alarm or reminder on mobile phones.

Exploring treatment options

Alternate therapies are popular with patients as they try anything possible to get relief. The only participant from an Eastern country, Emma is a UK expat living in Singapore. Her Buddhist doctor suggested she watch a series of YouTube videos by a monk on dealing with chronic pain. Emma related this story about her nerve block being removed:

... on the YouTube video what the monk said is (what matters) is how you look at it and (patients should) say “ok well this is going to be fun” and just think of it in a different way. And sure enough it's never as bad as you think it's going to be. Emma

Many participants described spending a lot of time and money, visiting multiple practitioners both mainstream and alternate. Jackie had had CRPS for four months when I interviewed her, and she was desperately searching for a cure. This is a collection of statements from her interview which provide an example of the extreme efforts she went to:

I've also been having alternate therapies, I've been having acupuncture, private osteopathy and electric differential treatment. On my hand and wrist as well. I've been doing meditation and hypnosis. I've also done a whole day of chakra cleansing with crystal bowls. He banged these bowls. My God my hand was in agony. I went for a three-hour session of myofascial treatment – it was very, very painful. The Amazonian Sharmans use lowaska for healing. It's got DMT in it so it's a psychedelic drug. But it's been used by the Amazonians because it makes you open your 3rd eye and it expands the brain and all sorts of things happen. Jackie

I'm saying to myself I'm going to overcome this. I'm embracing my hand. I'm talking to it, I'm kissing it. I've been putting frankincense and myrrh and rubbing it into my arm. And I've been putting this wintergreen concoction on my hand as well. But all of a sudden, I've been getting this rash. I've been scratching it and it's been bleeding. The guy who said to use it - he said it's because the toxins were being released in my body. Your nervous system has been shot to pieces emotional and physically since you had the break and you've got to clear out inside the nerves. Get right inside the nerves. Made sense to me. Jackie

After exhausting oral medication, physical therapy options and alternative therapies, many patients opt for surgical intervention:

So, the 2nd lot of Botox did absolutely nothing, so I'd ended up talking to my specialist about a baclofen pump and I've just realised that I've left out that spinal cord stimulator. Laura

Although none of the interview participants in this study have required amputation, many have considered the possibility as it is a known option for some. There is debate amongst health professionals as to whether amputation is appropriate for people without skin breakdown complications and patients often struggle with the decision to amputate or not.

So that's my next thing they offered me, was amputation. And that is still an option as far as I can see. You know if it gets really bad I would seriously think of it. But on the flip side of that, I'm told that with amputation you're still getting those messages going into the brain. So even if you've got your limb or you haven't got your limb, it's still going to hurt whether you've got the limb or not because of phantom pain. Paul

On the Burning Nights website Victoria describes having both legs amputated above the knees due to open ulcers on her legs causing skin breakdown and infection. She was unable to tolerate a prosthetic due to pain and now is confined to a wheelchair and experiences excruciating phantom limb pains in both legs. Readers are referred to the Burning Nights website for further information regarding spread and amputation.

Spread and fear of spread

Those patients achieving remission or stability of their symptoms are always at risk of a re-emergence of the symptoms especially following injury or surgery. This is often considered to be a spread by the patient:

And then I suffered a Meniscal Tear when I was twenty or twenty-one, and that complicated everything. So that actually led to me being in a wheelchair because I could deal with the CRPS in my foot, but once it spread up to the surgical site in my knee, it was really unmanageable. Jasmine

Spread also occurs seemingly without reason:

And also, it's actually started to spread down to my right-hand side and my right arm, which is rather bizarre. Because it started off down the bottom and it's now starting to creep up into my right side, which I think is totally bizarre. Paul

I: Was there anything that triggered that spread that you're aware of?

Well it could have been the stress of moving house and getting divorced I expect, that could be a contributing factor. It could be. I don't know how to prove it or disprove it, you know. Paul

Fear of spread can be debilitating to some people and it is a large topic on the internet where people report no longer shaving their legs in case they nick themselves. Patients post photos of every minor injury and post about stubbing toes and asking, “will this cause a spread”? or “does this look like a spread”? Catastrophising to this extent, interestingly, was largely a finding on Facebook. Interview participants discussed thoughts they get from a new pain:

I often get pains around my jaw and face and stuff and you often wonder why? I haven't been tensing up. I haven't been clenching. What are these from? Are they just sort of neck pains that are moving around? So, I just try and ignore a lot of other pains, you know what I mean? You just get a pain somewhere out of nowhere and you're just like: no, it's not spreading, leave me alone, go away. And I will touch that area. I will desensitise that area immediately if I feel pain anywhere else that it shouldn't be there. My knee's sore for some silly reason. I will touch the hell out of it and ensure I desensitise it. I do not want it anywhere else. I wish it just stayed in my arm, I really do.
Fred

The concept of spread is disputed amongst health professionals:

I have a problem when they talk about it as CRPS in their organs. Or CRPS in their teeth because part of the diagnosis of CRPS, and the essence of the condition, is an association with oedema and skin colour, and temperature changes. And you can't get those things in internal organs or teeth. So, when I hear that, what I think is they are referring to a sensitisation throughout the whole body. So, the things that maybe weren't painful before, or were only mildly painful, now hurt a lot in their organs or teeth. And that is I think, one particular, it is like central sensitisation. It is a mechanism rather than CRPS itself. HP1

I guess I fundamentally have difficulty with the concept of spread. Particularly because ... I've seen that happen very infrequently. On the other hand, I understand neurophysiologically that people can develop a sensitised nervous system and they may develop neuropathic pain that has other manifestations systemically. (...) So, does that person have symptoms of pain and dysfunction that may impact their bowel function? Absolutely! They have an immune system and a hormone regulation system that is completely disrupted; so, from the disease itself or the secondary effects, and/or the medications that they have been taking. Is that CRPS of their internal organ? Hmmm, I am not sure. HP2

HP2 however recognised that semantics in this instance is not useful:

Saying spread is not possible can create conflict within the caring relationship that probably isn't going to be productive and it probably isn't going to change the overall management for that person. HP2

BATTLES WITHIN THE WAR

Wars consist of several smaller battles. If CRPS is the overarching war, then various challenges are smaller battles within the war. This theme is built on sub-themes of:

- Accepting less from your body;
- Pacing;
- Moving the painful body part vs causing a flare;
- Guilt;
- Loss;
- Financial considerations; and
- Judgement from others such as disbelief of pain or unhelpful comments from HPs.

Accepting less from your body

The onset of CRPS results in the patient having a body that does not do as much as it used to:

It's still quite difficult (...). In the space of a week I went from somebody who goes to the gym three times a week, runs twenty or thirty kilometres a week, and was quite a keen cyclist and my job was very active (...) to limping around my house. Martin

Daily challenges occur, and new challenges can appear:

The most challenging thing for me now is walking. I have an electric scooter now to get around, because I can't walk very far. That is an almighty challenge. Eating is hard because I can't use this left hand to use a fork or anything, so my husband has to cut all my food up. Carolyn

Sleep is often a problem for patients and a term which can be found on CRPS Facebook sites is 'painsomnia' which means not sleeping due to pain. Patients often require extended sleep and day naps following big days. This is frustrating particularly for those who previously led full lives and must adapt to doing less each day and stopping before things become painful. There is difficulty in stopping before pain starts particularly when you are having a 'good' day or have a lot to do. Karen went to the dentist and called in to the shops on her way home. She described returning home and the next day as follows:

I was out of it for about two hours and the next day I went to get up. Couldn't move. I was sore from the crutches. Because I'd walked so far on the crutches. I was on fire – I had electric shocks and my leg and foot was burning. And I had so much pain. Even my hair was sore. (...) Not my head. My hair. (...) My hair's sore. How ridiculous is that. I was gone for the whole day. I couldn't move. I was in my pyjamas the whole day. Karen

Pacing

Patients are taught to pace themselves by doing small amounts of an activity at a time. Both Jasmine and Laura were diagnosed as children and know the effect an outing can have on their bodies:

If I go out to dinner or something, and a movie afterward, I'll have to spend the whole next day pretty much recovering from that. Jasmine

I have a couple of naps in the afternoon and if I spend more than a couple of hours out or even sort of here (at home) with visitors, I just crash, and I start wobbling, I start shaking. And I'm ready to keel over if I do too much physically. My problem is that I know all the principles of pacing and I'm not always so good at applying them and so I'll go, go, go, and I won't necessarily feel any pain and then I'll stop, and it will hit me. Laura

Moving the painful body part vs causing a flare

Patients are also taught to: "use it or lose it", which means a person needs to move their affected body part as much as possible or risk losing the ability to use it. As with pacing, it is difficult to limit activities during a good day to not overdo it and cause a flare.

Guilt

Guilt had many causes. Increasing the burden on partners and family members was often mentioned, such as no longer working and contributing financially to the household income and not performing household chores such as cleaning or mowing lawns. Guilt also came from being the cause of changed plans. Karen described aspects of her changed life which she felt guilty about:

Well my husband has to do everything (...). He does all the cooking, all the cleaning, all the shopping, all the washing. (...) lots of things revolve around whether I'm up to doing it or not. (...) We don't socialise much. We used to go out all the time. (...) Just don't go anymore – always make excuses and say I don't go. We don't, I don't even go to the football any more. Karen

I'll just take it really slow and do things but it's just so hard and you feel so guilty because, you know. You don't feel like you're pulling your weight. Karen

I think the stress of it makes them (parents) fight with each other. (...) I sometimes get the guilts. And I know rationally it's not my fault, but you still have the dark days where you think, well this is shit. This shouldn't be happening, and I should be able to do something about this, pull my finger out and make it better or make it easier on them or whatever. Laura

I can be a mess sometimes, I'm not even conscious for several days so the kids get themselves up and go to school sometimes if my wife has to go a little bit early and I feel so guilty. I'll be in the toilet vomiting, see you kids, goodbye. Fred

Loss

Besides coming to terms with the loss of their former body, participants dealt with loss of jobs, friends, mobility and independence. As with the notion of guilt, loss is in keeping with the chronic pain literature described in Chapter 2. Of the 17 patient participants, two had never worked and were university students at the time of interview, 11 had given up work and were no longer working and two had changed jobs due to their condition. Only two people were still working in the same position as prior to their diagnosis:

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

Yeah, I have lost a couple (of friends). Because they don't understand it and it's boring isn't it. It's boring being long term ill when you don't have; you know I do have things to talk about, but it's not like I'm going out and having loads of new experiences. Sarah

Financial considerations

The four participants undergoing insurance claims all stated it was a very stressful process for little financial gain and a court case was a huge financial cost for Mel:

Financially, I mean it wasn't a huge amount of money. Um ... obviously any amount of money is better than nothing, but it did take a lot out of me. It was very, very stressful. Karen

It's ruined me. I've used all of my savings that I had, and just sort of try and make it fortnight to fortnight. Mel

Paying for medication and private health practitioner appointments has a big financial impact. Before Lyrica was on the Pharmaceutical Benefits Scheme, Australians who could afford it were paying \$160 each month. There are waiting lists for most public health services but paying for private health practitioners was not sustainable for most participants. Concerns were voiced that participants could not access practitioners such as massage therapists due to the cost involved, despite the health benefits following treatment. Financial concerns also related to transport as participants acknowledged that travel by taxi was costly and not all participants could access buses or trains. Those participants who could no longer work found accessing disability payments was also difficult. There was an increased financial burden on most participants families:

I had no use of either arms, but I wasn't disabled enough for a disability pension. Until the woman on the phone said, "You need to push the depression button". And once I said I had depression, then all of a sudden I got a disability payment. Sharon

I'd used up all my sick leave and I wasn't getting any money obviously from work. (...) I stopped seeing the private OT and went back to the hospital OT because it was free, and I could get a friend to drive me there. If I got massages it would relax me (...) but there was a cost involved in that. But then I saw a naturopath, and there was a cost involved in that, and an osteopath. And I was complaining to my GP how long it took to see the pain physician at the hospital and how difficult it was to see him, and he said, "Well you can always go private". And I couldn't afford it. I just couldn't afford to do it. Colleen

I think it's also been a financial burden on my family for my medical bills and things like that. Alice

Judgement from others such as disbelief of pain or unhelpful comments from HPs.

Friends, family and health practitioners can be very judgemental about many aspects of CRPS but especially medication and pain. The pain experienced by patients can be compounded once they begin to learn about their condition. The McGill Pain Scale is publicised on many CRPS support group websites defining CRPS as the worst pain known to man:

McGill Pain Scale? I think that's a sign of distress when they do that. HP4

Unfortunately, patients can present to hospital in a flare and be disbelieved about their pain levels which further affects the psyche of the patient:

I mean my own doctor doesn't do it, but I've had nurses, doctors in hospital doubt me when I've told them what high pain levels ... (...) When I've had high pain levels I've told them that and they've doubted me because they say "Oh you look fine, you've got a smile on your face" or something. "You know you wouldn't be smiling if you were really in that much pain". Laura

Unfortunately, pain that severe can require opioid medication which is deemed not acceptable by some hospital staff:

You're the devil's spawn if you are taking opioids of any type, so they are very down on you about taking that. Sharon

Being believed about pain intensity did not necessarily result in better care. Jasmine described multiple visits to the Emergency Department and receiving less than optimal care:

Well not that they haven't believed that I'm in pain, just that they believe I have CRPS so of course I'm going to be in pain. It's like their automatic assumption is that I'm already in pain so why would I complain about any extra. Also, their attitude seems to be, because people don't seem to understand what it's like to be in chronic pain. So, when you go into an emergency room, if you have something on your chart that they only understand is that you're in pain all the time and you're complaining of pain. They're just going to think you're a drug seeker, like they don't help you. Jasmine

DEVELOPING BATTLE PLANS WITH ALLIES

Patients must form plans for dealing with their health issues and require others to support and assist them. Support doesn't necessarily come where you expect to find it. Some health professionals are better than others and some know about CRPS and some don't. There is a centre in England that specialises in CRPS treatment but not all English doctors are aware of it. Patients find out about such centres from each other because people with CRPS often talk to each other in online forums, on Facebook etc. and they become friends – or allies swapping information all the time. While many of the participants belonged to internet support groups, and said how many friends they had made, many of them also acknowledged that online groups may not be supportive. Participants revealed some internet groups are depressing when members try to outdo each other in terms of who has the worst symptoms or the most pain. Catastrophising seems to be worse on closed Facebook sites. Within this theme, the following sub-themes are pertinent:

- Patients must often advocate for better treatment;
- The value of multidisciplinary health care teams;
- Family support; and
- Finding support outside the family.

While each patient must find treatment and support, it is not a continuous battle for those who have a milder condition or may have access to knowledgeable multi-disciplinary health professionals, and some people have excellent support readily available. Patients described multiple appointments with a wide variety of health professionals. Table 5 provides an indication of how many different health professionals each participant had seen during the course of their condition. The list is not exhaustive as participants were not asked to list each HP they had seen (Refer to Table 5).

Chapter 4

Table 5. Health professionals seen by patient participants

Health practitioner	Rosemary	Karen	Jasmine	Colleen	Sharon	Laura	Dianne	Carolyn	Alice	Emma	Paul	Hannah	Sarah	Martin	Fred	Mel	Jackie
Surgeon	XXXXXX	XX	XX	XX		XXX	XX			X	X		X	X	X	X	X
Specialist doctor	X		X	X					XX			X	X			X	X
Physiotherapist	XXX	X	X	X	X	XXX	XX	X	X	X	X	XX	X		X	X	XX
Occupational therapist				X	X		X						X	X			
Psychologist	XX	X		XX	XX						X		X	X	X	X	X
General Practitioner	X	X	X	X	X	X	XX	X	X		X	X	XX	XX	XX	X	X
Pain specialist	XXX	XXXX	XXX	X	XX	X	XX	X	X		X	X	XX	X	XX	X	X
Exercise Physiologist					X												
Pain clinic*	X		XX	X	X		X	X			X		X	X	X	X	

*Within a pain clinic, participants may have seen any combination of the health practitioners above and some clinics employ additional staff such as registered nurses or nurse practitioners. X indicates each health professional seen by the patient participants.

Patients must often advocate for better treatment

Finding knowledgeable health professionals can be difficult yet patients are often advised to find a good practitioner. Unfortunately, at first, people don't know if their practitioner is appropriate for them or not until they have learned more about their own condition. Health professional interviews revealed a lack of knowledge amongst other health workers:

What I do know from clinical practice is that we still get people referred who say my clinician knew nothing about this condition. HP3

Patients advise each other of the names of health professionals and clinics they find helpful. There is often a long waiting list to see specialists, and referrals to them or to pain clinics are not always forthcoming:

I was doing my own research. I was trying to find services that could help people with CRPS. I had been to see my GP and had asked to be referred to a centre in [Place] in the UK that specialises in CRPS. And he refused because he said it was too expensive. Dianne

So, I've spoken to a couple of people on the forum and a couple of people see some really good doctors. I managed to get into one that a couple of people go to and have been going to for years. I didn't think I'd get in, but I did. I've got an appointment in August. (...) He's right on the other side of the city but I don't care. Karen

Patients are often in such a dependent position that they find it hard to advocate for themselves:

Because the hardest thing is that my life is not my own. You make the decisions as to what my life is going to be, and I've got to do whatever I can to convince you to help me because I'm stuffed without you. Sharon

I fought this woman for two and a half years. I kept asking for another doctor, they didn't do that. (...) I wanted a second opinion; how could I get that? I ended up having to write to the hospital board. Like the complaints area, just saying I really need this and that was rejected a number of times. Sharon

Karen described the fears patients face when they decide to ask for better care:

Um, I think it's just important not to settle with what the doctor says. If you're not happy to question it. To move on. Not to stay with the same doctor if you're not happy. (...) I think a lot of people have this fear that if you question the doctor, then it's just going to blow up in your face. (...) it doesn't matter whether they're in the public system or the private system, you've got the right to be treated like a human. You know you put your stuff forward and get the treatment that you deserve. Karen

The value of multidisciplinary health care teams

Participants who had contact with multidisciplinary teams often described better treatment than those who did not have the same access. Health practitioners also recognised the benefits of a multidisciplinary team:

I think the next best thing ... is multidisciplinary pain treatment where you include the psychological pain management component. Like changing patients who are worriers into warriors. HP1

It must be a comprehensive, large, experienced program, ideally for these patients. We need to have some sort of referral program whereby these long-term patients are seen by just a few centres nationally ... they really deserve that expertise. HP4

Carolyn had 18 years of experience in living with CRPS when interviewed and with multidisciplinary support, she has been helped to find solutions for many problems, including being able to touch her grandchild:

When my little grandson was going to be born, I was actually in [Place] at the time, or near the time, and the physios down there are amazing. And we worked on the baby touching my arm, the weight of the baby on my good leg. I can't put it on my left side. And again, when the baby was born they helped me (...) But I overcame it and I held my little grandson. If he comes up to me and he touches my leg, it's not nice. But he's so lovely that I just think that's sore but who cares, he's super so I just deal with it really. Carolyn

Family support

Many participants and their families have found novel solutions to problems and Carolyn had good examples:

And like when we go shopping my husband always stands that left side because I am paranoid, I suppose, about getting it bumped (...) my daughter does it, and both the boys do, and their partner, or husband, or wives or whatever. I think we're all aware of it, so everybody sort of just keeps to that side, which helps. Carolyn

I can't remember which one of them it was, but I wanted to butter my own bread. So, they got a biscuit tin (lid) and Blu Tac'd it to the worktop so that I could put the bread in the corner and I could do it myself. They came up with lots of different things. My eldest son is an electrical engineer and I wanted to do the ironing, and he made me a footpad so that I could turn the iron on and off and silly things like that, but just made life as normal as possible. Carolyn

Finding support outside the family

While many of the participants belonged to internet support groups, it was acknowledged by both the patient and health professional cohorts that they are often not supportive and can be depressing when members try to outdo each other in terms of who has the worst symptoms or the most pain, ignoring positive stories and downplaying the attempts of others to raise awareness:

Posting in groups over and over again, every day, like how debilitated you are and how you can't go out, and how your friends don't want to be around you, like it's just a self-perpetuating cycle. I don't want to feed into people's self-pity and misery, because there's nothing we can do about our situations. The only thing that we can do is make the best out of them, and I don't think the groups are very conducive to that kind of mentality. Jasmine

Some internet groups are more supportive than others:

How do you find all the forums and things? Lifesaver, literally a lifesaver. I think if I hadn't found the [Name] site, because that's the first one I ever found, I don't think I'd be here. The people on that and the support they gave me, I'm gunna tear up now. (...). And yeah, one of the people on there is now my best friend in the world {Crying}.
Laura

Some health practitioners offer valuable support:

My pain psychologist is really good. It's just somebody to (...) blow steam off with really. Not anger or anything like that really just um your little bit of frustration but more your um 'what ifs', and your 'I wish I had ofs', and 'it isn't fairs' etc. that you would never burden your family or your friends with. He gets paid to worry about you. He's good. I don't have a problem going there. He has a really good knowledge of CRPS and I think that to see a pain psychologist he is specifically a pain psychologist. (...) it's preferable for them to have a good knowledge of CRPS, if they don't at least they have a good knowledge of chronic pain. Karen

Doctors seem to want to quantify pain and ask for descriptions of pain, but participants stated they sometimes find it difficult to express their pain and its extent or convey an understanding of its intensity. Many participants spoke about a lack of understanding on the part of the health practitioner:

But it's trying to tell someone that on those days when it's that bad, that just the weight of your feet hitting the floor ... like I'll inch along. You must know where the pain is just burning that much that you're walking on your tippee toes because each step is trying to tell someone the magnitude of the pain! Sharon

They (health practitioner) should realise that each day is different. That pain is ... you can't see a person's pain. A person on a good day might look perfectly normal. But that

night they'd be very different. They need to realise that because a person can do one thing one day, or one week, doesn't mean they can keep doing it. The next week things might be very different. That pain and the limitations vary. They need to realise that with CRPS on the whole it's progressive. That people don't get better from it. I just think that they need to have a better understanding that this is very real. Rosemary

Rosemary expresses the difficulty in describing the extent and severity of her pain:

People will rate a 10 out of 10 pain. Some people their 10 out of 10 pain could be a 5 out of 10 to me so it's all sort of relative. It's so hard to explain that this pain is really severe. It's worse than childbirth. How do you explain it? I took a couple of movies of myself having a pain flare before the implant. That's when the pains were 10 out of 10 shooting pains. When I have those pains, they jolt my whole body. They come in succession. I'll be sitting there every time I just ... can't help but physically react to them. That's the closest I come to showing pain. And it really doesn't tell anybody what it's like. This pain that I have – the burn pain, yeah, it's there most of the time. But that's not what gets me. It's the severity and it's the spontaneous nature of these shooting pains. I never know when they're going to happen. They get me unawares every time. And they're just so unpleasant. They're just horrid. They absolutely just shatter you. How do you get this across? Rosemary

Participants agreed that HPs require better knowledge of the condition and had suggestions for what they should know about living with CRPS. Some knowledge that the condition exists would help people who must present to a clinic or hospital other than their usual care provider. Knowing to ask before touching was another point mentioned by the majority of participants:

I think that they definitely should know whether it's ok or not to touch you. Because I've even found like supposed pain specialists who will just reach out and grab you. (...) I think they need to understand that not everybody with CRPS is the same. Karen

If pain management physicians instead have the attitude like, well there's this cutting-edge treatment going on in Europe, but since it's not available in the U.S., while we're waiting for that why don't you join these chronic pain support groups. Or why don't you try these websites with innovative solutions for your depression, or whatever. Jasmine

If they become pain management specialists, they need to do a really good course and become more knowledgeable about this disease and they need to talk to some people like me. They need to talk first hand to people who've had it, been diagnosed late and been through... who know what it's like and for God's sake believe them. Rosemary

WARRIOR OR PRISONER OF WAR

The word warrior is often used in conjunction with fighting illness. The warrior attitude is taken on these occasions to mean a person who has shown great courage, vigour or aggressiveness with the mental toughness to decide to be in control and not let events control them. Some people with CRPS catastrophise the condition and suffer immensely while others seem to rise to the occasion and develop good coping strategies by overcoming adversity and becoming resilient. Participants spoke about defining themselves in an altered body and feeling vulnerable or rising to challenges presented to them. Occasionally, the issues were too much to handle, the warrior attitude was lost, and a prisoner of war persona took over. The prisoner of war is a person who is captured and held by an enemy during war (Cambridge, 2018). The prisoner of war persona in this circumstance is someone who feels without choice, under the control of CRPS, and not physically or mentally free to make choices. Luck was often discussed in the perspective of being a warrior or prisoner of war. The sub-themes explore the notions of the following:

- Hiding behind a mask;
- Unleashing the warrior within;
- Confronting problems; and
- The prisoner of war.

Hiding behind a mask

There are many reasons patients do not disclose their pain levels. For some, it is a mechanism to protect those around them from the pain of seeing a loved one suffer; for others, it is to appear normal and not stand out in a crowd. Sometimes, people pretended to be more well than they felt because to give in would mean to break down and lose control:

I think and especially the longer you have it you learn to put a mask on. Because you, I don't know it's self-protection or protecting others or what but yeah, I mean it's certainly something I do is hiding how you feel, hiding how much pain you're in. Laura

When I was really young no one quite knew what to make of it and so I kind of pretended that it didn't exist, like I was able to get along. I walked okay. I couldn't run that well, I had a kind of a funny run, but when you're a kid you try and hide anything that makes you different from other kids. Jasmine

Unleashing the warrior within

Consultations with a psychologist or psychiatrist were instrumental in helping participants adopt a positive attitude to living with their condition and as shown in Table 5, most

participants had seen one. Other health practitioners knowledgeable about CRPS do their best to give patients the tools required to help themselves but may not always understand how difficult it can be for patients to help themselves. This is more difficult for those who do not have access to practitioners with CRPS expertise:

This is very much about a relationship and patients' choice. Clinicians give information and then it's up to the patients to choose what they wish to do with it. HP3

Most participants described difficult times and times of depression particularly in the early years following diagnosis. Different techniques were used to change their attitudes to become more positive:

There is a choice in that either you decide that you are disabled and go down a very negative path, and think that it's spreading, and make yourself very ill with it. Or choose to try and live with the pain mainly and get on with your life as much as possible. And not see yourself as disabled. Obviously acknowledging that there is a disability, but that you can still have a really good quality of life. But I think there is a very fine line. I think it is very difficult to tread that line and this is where the help needs to come in. And getting the psychological support, I think, early on for people who are struggling with pain, to try and keep them positive, and engaging with life. Dianne

About 4 years into CRPS I was seeing a really good psychologist locally, fantastic and I was really looking at feelings of grief where I had this belief at this stage where I would never stop feeling the grief... (...) So, she challenged that. She said you can sometimes get off the river. And you can enjoy the times when you don't have pain. I started thinking about this and I thought yeah, you're right. Now at that point I was sick of the tears. (...) I was sick of spending all this energy on crying and being depressed and pain. I'm going for life and I'm going to learn how to sit on the river bank and enjoy the times in between and find a way of living with this. I think you've got to reinvent yourself. You've got to find a way in whatever disability or limitation you've got; you've got to find a way forward and it just involves forgetting about the way things used to be - what can you still do? Rosemary

I think the most important thing for anybody, I always say, (...) is don't give in to it, you mustn't give in to it. (...) You've just got to control it to the best of your ability I suppose and try and live life to the full if you can. (...) I won't let it stop me doing things. I might not do it the same way as I would have hoped but I won't let it stop me, I won't let it. Carolyn

Health practitioners questioned the best way to activate resilience factors in patients and felt that using the warrior terminology was appropriate. Keeping an open mind and being a flexible thinker and being open to finding new ways of doing things were attributes the HPs thought necessary to have in order to achieve better health outcomes:

Yeah, I have heard the term CRPS warrior (...) I think it is nice in a way because it's like trying to take some power over the condition. (...) part of taking power over the condition is doing what you can in terms of your own behaviour and thought process, to try to deal with it better. (...) And we don't have a cure and I think the only way to (...) be able to live better with CRPS is to kind of take that warrior attitude of, of well, I am going to learn to do this. And I can learn to do this. And all of that may help a little bit. HP1

You can understand in chronic conditions people talk about battling it, that they will overcome it. Because they feel that if they accept, they give in to it (...) therefore battling it and being a warrior is entirely appropriate within that context. HP3

Some participants recognised the mental strength and other qualities within themselves that led them to adopting a warrior attitude:

Like yes, I have CRPS and yes, I'm in pain all the time, but it seems to be more manageable for me than the average person. Like I seem to be able to function despite it, I guess just through will power and growing up with it. And having force of will being kind of a defining part of my character, but I always just pushed through it. I'm not stuck in bed all the time, even after my car accident, I wasn't stuck in bed all the time, even though I couldn't push my wheelchair. And it's just kind of a personality thing. Jasmine

So, I count my blessings. Great husband. Great house. Being able to find a way. An identity to fall back on. My art, it's just saved me. Well a lot of things have saved me. I think it's my art and if I look at it I think maybe it's just part of who I am. Rosemary

Once patients have their condition under control and feel mentally strong, they often started raising awareness. Some started their own internet blogs or Facebook CRPS awareness groups and patients have started charity and support groups such as Burning Nights and The Purple Bucket Foundation. Others joined campaigns such as Colour the World Orange, which is an awareness campaign where landmarks throughout the world are lit in orange for a night. Health practitioner reactions to this campaign ranged from participation to believing awareness campaigns for health professionals are more important than for the general community:

I want to get involved in the CRPS "Colour the World Orange" day. (...) I get really frustrated with the amount of people that are raising money for cancer, and you want to do some promotional thing, to make people aware of what you have (...) It's frustrating that you have to do it when you're a sufferer yourself. Sarah

I had a nice orange shirt on on Monday. HP2

Colour the World Orange? No, I don't think I've heard of it. Is this a CRPS campaign?
HP3

I am not sure that making the general public aware of what CRPS is [is] all that helpful since they are not the ones that are going to have contact with the patients routinely.
HP1

Confronting problems

The participants tried to get on with their lives and often had unique approaches to solving problems, such as Paul who got a custom-made mobility aid for his son's pram so that he can control the pram with his waist and use both crutches at the same time. Paul also changed his car to one that sits quite high and has a hand bar to assist with getting in and out. Sarah bought a vehicle which accommodates a mobility scooter and a hoist and other participants changed from manual to automatic vehicles. Losing independence was one of the most common problems the participants dealt with:

It's not safe to drive anymore. So that's one thing I have given in to, but I hate. And that's quite a battle to myself to not be independent anymore. (...) I think losing my independence is my biggest thing. Carolyn

... I now live at home because of the money situation because I live on a disability pension. I don't walk around, so I'm in a wheelchair that limits me obviously. Some places aren't wheelchair friendly. It can be frustrating. Alice

Participants had novel solutions to regain lost independence due to reduced mobility:

I have the knee walker which I found online, and had it sent out from America. And that's been an absolute lifesaver because I can whizz around on that. That and the crutches I can do quite a lot. Rosemary

I'm having a custom wheelchair made at the moment (...) Just a normal wheelchair but it's a power assist. So, when I'm going longer distances like shopping I can go in my wheelchair, so I've got a bit of independence (...) I'll be able to go out on that then. That'll be fun. Karen

Shopping and cooking were an issue for many participants and various solutions were found for everyday problems such as shopping on the internet and home delivery of groceries.

Chopping vegetables was an issue for most participants with upper limb CRPS:

I can't peel vegies anymore... I buy frozen vegies. I use my left hand to stir, like mince, and use my slow cooker as much as I can. Mel

I can't lift a kettle, so I've got this, I'm not totally sure how to describe it, but it's basically like a coffee maker only it just dispenses hot water and so I've got that

because then all you have to do is press a button and it dispenses it for you rather than having to lift it. Hannah

Other household duties also required problem solving approaches. Although an expensive option, putting clothes through a dryer was identified as easier than pegging clothes on the clothesline one handed. Household chores were often left undone by those who could not afford a cleaner etc. and many participants were grateful to family members for performing chores such as lawn mowing or vacuuming. Eventually, participants found strategies to solve their individual problems. Hannah has lived with CRPS since she was a child and finding alternative ways of doing things has become second nature to her:

There are occasions when cutting up food and cooking are obviously a problem but, now that I think about it, I do kind of adapt around that because sometimes I just eat things that you can eat with your fingers rather than have to cut up. Yeah and I've got a bra with a zip on the front rather than clasps which is helpful. (...) I haven't really registered how much of a change I've made. I hadn't really thought about it. Hannah

Wearing certain items of clothing is an issue seldom considered by health professionals. Those women unable to tolerate a bra described dressing to hide the fact, wearing baggy shirts and dark colours. Some tried to desensitise themselves by wearing a bra for short periods during the day. This is not something many routinely discussed with their health care providers:

Buttons, zips, they're all out. And the sensitivity of my arm, also there's a lot of things that I can't wear. I can't wear a bra anymore, because of the pressure that it puts on around there. And I can't do one up anymore anyway. Mel

I couldn't do my bra up, so I had the boys doing my bra up and they were saying, "Oh that's disgusting, this is the most disgusting thing I've ever done." Colleen

I hate putting my arm through my sleeve because it's sensitive. I cut all my sleeves off. They all get cut off until they are above the elbow where they flare out. Fred

Besides clothing issues, personal hygiene issues were a problem for many participants and attitudes surrounding this issue were varied. While some participants managed to use their non-dominant hand, others were unable to and were forced to find alternatives:

Doing my hair, I more or less, turn myself inside out to get it up. Washing my hair, I've changed to the pump shampoos and conditioners, so as I can just put it into my left hand and do it with my left hand. Toothbrush, I bought an electric toothbrush. Mel

Showers; I used to have showers every day. I only have them maybe once or twice a week now, because I have to get the courage up to actually have one because they are painful on my skin. Bathroom; I don't have any control over my bladder or anything

anymore, so I wear nappies because I do have accidents quite a lot. You know, I'm disabled. {Laugh}. Alice

Those participants unable to self-care faced issues such as the age and health of their carer and if the carer was not a family member, trust was a problem:

Fortunately, he (husband) likes caring for me, but you do worry that there will become a point you know, he's ten years older than me, that he'll get kind of fed up with it. He's already injured his back through looking after me. Sarah

I can't shower with it. I can't use a towel. I can't dress myself. So, I have carers come in to wash and dress me. (...) Some days they just don't show up! And that's the point where I think the depression kicks in. Sharon

Although health professionals recognise that some people cannot care for themselves, and for some, showering feels like needles hitting their skin, less common problems such as fingernail issues are rarely recognised by health professionals. While brittle nails can be managed by females by getting a manicure and gel or acrylic nails applied, the problem was not as easily solved in men:

(...) the consequences of that is that I suffer from very, very brittle nails now because of my calcium levels dropping. Paul

They're like two different hands now. My fingernails are completely bowed over and curved and they're brittle. Fred

Mum will try to cut my fingernails because I can't do it. But it's like I can feel them growing. So, to get them cut, it's like she's cutting a finger off me. Mel

The prisoner of war

Each participant described a difficult time when they felt unable to function properly. While each also described better, more positive times, the prisoner of war attitude of not feeling in control and of having no options was experienced by all participants for varying lengths of time:

The worst situation is a patient who is like the opposite of a warrior, who is totally passive waiting on doctors to do something that is just magically going to fix it. HP1

Fred described some of the more difficult times he has been through:

I can't do much. I can't go anywhere. I can't handle the wind on my arm. I can't even breathe on my arm when I'm sleeping, you know what I mean. So, it has a bit of an effect on my children that some party events like Easter when we go around to grandma's house, I may or may not be able to go. You know my family will, my wife and kids will, my mum hates it that sometimes I make it, sometimes I don't. Fred

My shoulders just seized up even though it probably doesn't have CRPS, but I've held my arm in this position for so long my elbow doesn't straighten anymore. My shoulder doesn't move much, and I've lost all the muscle in it (...), I've probably had the least amount of treatment than anybody for my condition. I didn't know where else to go or what to do. Fred

A big issue for me when my two youngest kids were around the age of two to six. I was terribly afraid of them, I could not even sit on the couch with them, they are too active and would hurt me, I hid away in my bedroom for years. it was the worst feeling ever to fear my own children. Fred

CRPS has the dubious reputation of being known as the suicide disease, particularly within the online CRPS community. Health practitioners' responses to this term ranged from not being surprised to outright rejection of the idea that there is a high suicide rate amongst patients. While some of the participants disclosed suicide ideation in the past, none admitted actual attempts.

BEAUTIFULLY BROKEN

As discussed in the previous chapter, a poem was used as another source of data as a literary form of lived experience. (Refer to Chapter 3, Methodology and Methods, Data Analysis, Textual Material). It is reproduced here in its entirety as a phenomenological example of linguistic expression describing the battle of living with CRPS. This poem describes the authors experience of living with CRPS and in doing so, manages to cover the themes that have been presented in this chapter.

Beautifully Broken

*She has a beautiful heart and beautiful soul
She's beautifully broken but pretends that she's whole.*

*Her spirit is vibrant, she's fierce and resilient.
She faces each day with perseverance so brilliant.*

*She's battling demons, she's fighting a war.
Her body feels broken, she can't take much more.*

*She's stronger than many but feels weaker than most.
Her pain makes her feel like she's only a ghost.*

*She lies awake in bed, her body is screaming in pain
But to others she's silent, she won't ever complain.*

*Each day it gets harder to put on a brave face.
She swears she's okay but feels like a disgrace.*

*She seems so put together, like she's doing just fine,
Nobody sees her storms, only her vibrant sunshine.*

*She's breaking in pieces, though she looks so complete.
She's the most beautiful disaster you will ever meet.*

*She's the queen of pretend, she's so very convincing
She seems to be thriving but she's barely existing.*

*Her mind keeps on racing, it's in constant overdrive
The dark thoughts creep in and make it hard to survive.*

*She's anxious, she's tired, depressed and exhausted.
She's stuck in a nightmare, she's constantly haunted.*

Chapter 4

*She'll never let you see the pain behind her eyes
Some days even she starts to believe in her lies.*

*She has a beautiful heart and a beautiful soul.
She's beautifully broken but pretends that she's whole.*

By Sarah Lesley.

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CHAPTER SUMMARY

This chapter has discussed the battle and the five themes which emerged from the participant interviews. Each person diagnosed with CRPS faces a battle. This is the essence of the phenomenon of living with chronic pain in the lifeworld of CRPS. Within this battle, patients' experiences fit within each of the following themes:

1. Dealing with an unknown enemy;
2. Building an armoury against a moving target;
3. Battles within the war;
4. Developing battle plans with allies; and
5. Warrior or prisoner of war?

Patients face a constant, daily battle: From fighting for a diagnosis, to learning to live with a changeable condition, dealing with symptoms, and side effects of treatments and medication. They may have allies in the battle by developing a support network and finding knowledgeable health care practitioners. Finally, patients may come to terms with the daily battle by acquiring the skills to overcome issues and live a quality life or succumb to the disease and become a prisoner of CRPS. These concepts have been outlined and many examples have been provided to allow the reader to connect with the data and understand how the participants told similar stories of battling every day to live with CRPS. The ideas presented in this chapter will be discussed further in the final chapter – Discussion and Conclusion.

CHAPTER 5: DISCUSSION AND CONCLUSION

INTRODUCTION

This research, which set out to discover the essence of living with chronic pain in the lifeworld of complex regional pain syndrome, has identified that living with CRPS is a battle. Patients often express themselves using fighting words to describe their existence such as in the poem by Sarah Lesley who writes “she’s battling demons, she’s fighting a war” which aligns with the language used on the websites, the book and by the patient participants in their interviews for this research. The themes discovered in this research were named to reflect the battle, the constant fight patients live with every day. These themes will be discussed in detail in this chapter.

THE ESSENCE OF LIVING WITH CRPS

First, to summarise the data. There is a war being waged. No one can see the enemy. Some doubt its existence. Patients know it is there because it has caused immense devastation. Losses have been great. Jobs, friends, and financial security count among the fallen. Pain, injury and emotional turmoil have arisen. What has caused this war? What is the enemy being fought? Patients try anything to identify and beat this enemy inside them. Family and friends may or may not enlist to join the fight. Health professionals are conscripted and in keeping with their training suggest strategies to overcome the enemy. If these strategies do not work, everyone, it seems blames the patient. They are either not properly following orders or there is no enemy. They have made it up. The enemy is a figment of the imagination of an attention seeker, a drug addict, a hypochondriac. Sometimes, the health professional has fought this enemy before and knows what to do. Mostly though, they don’t.

Eventually, the war is called CRPS. This war cannot be won. There are too many battles to be fought and too many skirmishes existing. The enemy decides to move and change. The enemy that was in the thumb (for example) has moved to the wrist. On a bad day, the enemy travels up the arm, into the shoulder and into the neck. In some people, the enemy jumps from the foot and into the arm. The limb that was previously hot and red and swollen becomes cold and changes colour. If a proper battle plan could be established, there might be a chance of winning. But, the weapon that once worked well in controlling the enemy has caused other conflicts. Weight gain, oedema, dry mouth, tremors, memory and concentration problems, severe constipation, dizziness, drowsiness and blurred vision occur. Allies with expertise are needed.

Few people have had experience fighting this war, so the expertise required is hard to find. The battle plan for each person must be individualised. What is used for one person does not work for another. The war seems to be raging differently in each person. The patient calls for more allies but sometimes the people who you would expect to help don't. The patient is left with a sub-optimal defence force and does not have the skills necessary to conquer the enemy. The enemy starts to win and takes control. The patient surrenders and becomes a prisoner of war. They have no control. They are dominated by CRPS. Most battles are too strong to fight. The patient loses hope. Suicide seems the only way out for some prisoners of war.

An approach using the skills of an entire army is required. The unique skills of each soldier combine to overpower the enemy. The commander in charge of the army mentors the patient and they become a warrior. They feel strong, they have skills. They can cope with the daily battles because they have an army behind them to help. The enemy is never entirely beaten but it can be subdued, and it can be controlled. Unrelieved pain is the biggest enemy of the CRPS patient:

Unrelieved pain can impair all aspects of a person's life, including appetite, mood, self-esteem, relationships with others, and even the ability to move. In some countries, it has been reported that unrelieved pain can lead to the wish for death and inquiries about euthanasia and assisted suicide. Relief of pain has been demonstrated to improve quality of life. (WHO, 2000 p. 9)

There are specific traits to CRPS that patients must battle which are not experienced by people living with other conditions. It is recognised though, that some other conditions such as fibromyalgia share some of the same problems and symptoms of CRPS. With pain as the central construct, people with CRPS experience all the concerns of living with a chronic pain condition and live with the added battles of CRPS which is represented by a pentagram in Figure 2. This figure illustrates the lifeworld of CRPS and the battles faced by patients. The use of graphical representation of the findings allows those who do not wish to engage with phenomenological descriptions of the battle of CRPS to gain an awareness of the complexity of living with CRPS. Figures though are descriptive; indicative of only one interpretation of the findings, and in order to truly comprehend and understand the phenomenon, the reader must enter into a hermeneutic dialogue with the text (van Manen, 1990, 2011) (Refer to Figure 2). The themes that emerged in this research will now be discussed in relation to the existing literature.

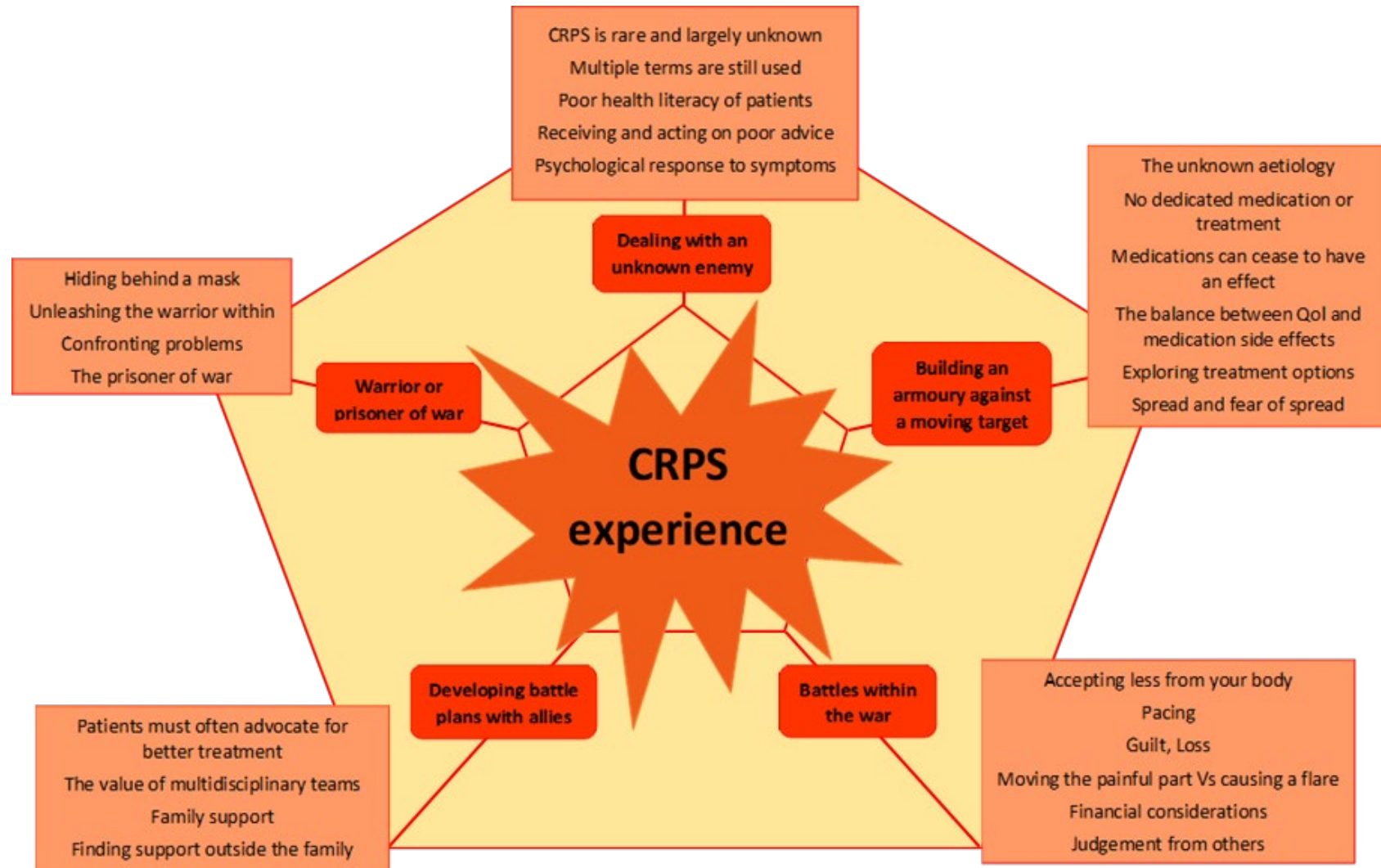


Figure 2. The Lifeworld of CRPS

DEALING WITH AN UNKNOWN ENEMY

CRPS is considered to be an unknown enemy in this research. This theme sits at the top of the pentagram in Figure 2. The major issues in this theme are:

- i. CRPS is a rare and little-known condition;
- ii. Health professionals are mostly unfamiliar with the condition; and
- iii. After struggling for a diagnosis, patients with little health knowledge attempt almost anything to find relief from the pain and accept poor advice.

Patients face difficulty obtaining a diagnosis because their condition is rare and has been called by many other names. Poor advice given by unknowledgeable health professionals is acted upon because many patients do not have the health literacy to know any better and are desperate to find a way to stop the pain. The usual course of events for participants in this research was misdiagnosis and/or delayed diagnosis, which caused patient participants to doubt themselves and question their mental health. They knew something was wrong, but had trouble being believed, often despite the florid physical signs such as redness, swelling, and temperature changes in the limb. They battled an unknown enemy.

Despite the increased understanding which has resulted from extensive research into the condition, CRPS remains largely unknown and misunderstood amongst many health care providers (Borchers & Gershwin, 2014; Bruehl, 2015; Elsharydah, Loo, Minhajuddin, & Kandil, 2017; Goebel, 2011). Being a rare condition, CRPS is not routinely taught to health care professionals during their initial degree and many practitioners will never encounter it clinically. As a diagnosis of exclusion and being dependent on patient reports, there are many differential diagnoses including fibromyalgia, post traumatic neuralgia, inflammatory arthritis and herpes zoster (Borchers & Gershwin, 2017), and misdiagnosis and/or delayed diagnosis is common (Binkley, 2013; Harden et al., 2013; Rodham, 2015). CRPS does not fit well with the medical model which requires observable signs and symptoms and a measurable biological cause, or single linear causality, or specific aetiology (Yuill, Crinson, & Duncan, 2010) yet research into the condition is largely quantitative research concerned with finding the cause.

Theoretical or hypothetical aetiology of CRPS is varied. The dominant models are that CRPS is caused by different pathophysiological mechanisms: a sympathetic nervous system disorder; neurogenic inflammation; and central maladaptive neuroplasticity (Ott & Maihöfner, 2018). One theory consists of subtypes such as a predominance of inflammation, central neuroplasticity, psychological and autoimmune factors (Birklein & Schlereth, 2015), while researchers such as Goebel (2011) and König, Schlereth, and Birklein (2017) believe CRPS is an

inflammatory condition which transitions into centralised CRPS characterised by brain changes and neuronal plasticity. According to Russo, Georgius, and Santarelli (2018), CRPS may be better understood as four components of altered function: tissue trauma, abnormal pain processing, autonomic imbalance and alteration in the immune system, although specific experiments to validate this hypothesis are yet to be completed. Each of the proposed models are evidence based to some degree, and the models are not mutually exclusive; there is an overlap in some theories, but most researchers agree that there is still much unknown about CRPS (Ott & Maihöfner, 2018). The health professionals interviewed agreed that there is more that is unknown in CRPS than in many other conditions and stated that this makes CRPS more interesting to many researchers.

Another complicating factor in diagnosis of the condition was the continued use of outdated names. Despite the 1994 adoption of the CRPS name, in the USA it is still often called RSD in clinical areas perhaps due to the International Classification of Diseases, Ninth Revision, Clinical modification (ICD-9-CM) codes used there such as 'reflex sympathetic dystrophy unspecified' and 'reflex sympathetic dystrophy of the upper limb' (Burgess & Fragoza, 2017; Elsharydah et al., 2017). Patients and HPs both discussed the confusion and problems caused from the continued use of multiple names such as RSD. Some of the problems caused were poor communication with and between clinicians not having a common terminology, and the use of imprecise terminology often leading to imprecise diagnosis, misguided treatment and incorrect evaluation. According to Borchers and Gershwin (2017), research has been misdirected for decades due to the use of RSD instead of CRPS.

Many patients did not recognise when they were being given inaccurate information or inappropriate treatment as they described searching desperately for a cure and consequently trying anything to find relief from pain, even if it sounded far-fetched. Many patients have poor health literacy and do not understand medical terminology or research findings. This leads to misinformation and wide dissemination on CRPS internet sites of potentially dangerous and incorrect ideas such as vaccination for the Human Papilloma Virus (HPV) causing CRPS (Head, Wind-Mozley, & Flegg, 2017). There is a vocal group of people online who believe this incorrect information and do not vaccinate against HPV and encourage others to also withhold vaccination. Byron Richards, a Clinical Nutritionist, reported that Lyrica is a death sentence for new brain synapses and his misinterpretation has led to the notion of Lyrica causing brain damage (Dobberstein, 2017). Many patients refuse to take Lyrica as prescribed without critically questioning the neuroscience knowledge of a nutritionist, choosing instead to mistrust the medical research-based evidence provided by their doctor.

There is an emotional component to the development of CRPS which is not often acknowledged in CRPS research literature. Chronic pain research recognises that intense pain causes normal activity to cease and the focal point of attention becomes the pain; it monopolises the consciousness (Serrano de Haro, 2016). Participants reported that the continuing pain caused loss of self-confidence, panic attacks and they described themselves as more emotional than usual. Health practitioners described attempts made to alleviate this initial distress by providing information leaflets, recommending websites or converting medical information into layman's terms. This was extremely helpful to the patients who had contact with HPs knowledgeable about CRPS because they could be assured that their feelings were valid. For others, undiagnosed CRPS, similar to other undiagnosed chronic pain conditions, led to vulnerability and suffering (Furnes, Natvig, & Dysvik, 2015) and the accusation that the problem is psychological (Ashe, Furness, Taylor, Haywood-Small, & Lawson, 2017). Pain may be more exacerbated by psychological factors such as anxiety and depression in CRPS patients than those without CRPS due to sympathetic nervous system arousal and the potential impact of sympatho-afferent coupling (Bruehl, 2015). Stress-induced release of catecholamines have also been implicated in the intensity of CRPS pain and emotional distress can not only sustain pain but also be a consequence of pain (Bruehl, 2015; De Mos, Sturkenboom, & Huygen, 2008).

BUILDING AN ARMOURY AGAINST A MOVING TARGET

After fighting for and receiving a diagnosis, the next major battle for patients was finding a healthcare team who understood CRPS and could assist in dealing with symptoms which come and go. The word armoury as used here, is intended to mean "things or qualities that can be used to achieve a particular goal, including weapons and equipment" (Cambridge, 2018). The goal being to treat CRPS. The second theme in Figure 2 sits at the 2 o'clock space. The major issues in the moving target theme are:

- i. Lack of confirmed aetiology;
- ii. Lack of agreed upon manifestation of the condition; and
- iii. Lack of shared and agreed language between HPs and patients.

This theme involves the difficulty of treating CRPS because there is no known dedicated medication or treatment. Because CRPS is known to change over time, medications may suddenly stop working. Patients may also decide to stop or reduce medications due to the side effects. Spread and fear of spread are major factors for patients.

CRPS is a moving target because it changes from peripheral inflammation to cortical reorganisation over time with different signs and symptoms appearing at different stages of the disease (Casale, Atzeni, Masala, & Sarzi-Puttini, 2015). The fact that some patients experience sympathetic nervous system activation and oedema just from thinking about moving, and that in some, the non-affected hand will change temperature if it is brought into the space of the affected hand, further reinforce the moving target notion (Birklein & Schlereth, 2015). Although the pain remains, most of the peripheral signs such as distal limb sweating, altered temperature and oedema fade or disappear once the condition becomes chronic (Goebel, 2013; McCabe, 2013; Russo et al., 2018) although the clinical picture can change on a daily, or hourly basis in some patients (McCabe, 2013). Flares can bring back some symptoms such as swelling, and temperature or colour changes, the condition can move to other body parts and a switch in pathophysiology during the course of the disease has been suggested (Birklein & Schlereth, 2015). Distorted body representation is thought to be caused by disruption to the Central Nervous System, or to neuroplastic brain changes and some patients mistakenly believe their limb is swollen and report feelings of foreignness and perception that movement of the hand is out of their control (McCabe, 2013; Reinersmann, Maier, Schwenkreis, & Lenz, 2013). According to McCabe (2013) some patients have a strong dislike of their affected limb and up to a third of patients experience referred sensations. For example, the patient experiences a sensation of touch on the left side of the face when the left hand is touched. This does not occur with other types of chronic pain. For example, back pain stays in the back and headaches do not migrate to other body parts.

Living with CRPS was described by HPs as more difficult than living with another chronic pain condition as it is more complex than other conditions, interferes with functioning more and the journey to diagnosis is often more of a challenge due to the amount that remains unknown about it. Despite the attempts of many committed research teams throughout the world, CRPS remains a disabling disease, with no specific therapy (Burgess & Fragoza, 2017; Elsharydah et al., 2017; Harden et al., 2013; McCabe, 2013). The unknown aetiology leads to the lack of specific treatment although Birklein and Schlereth (2015) believe that the significant advances in CRPS understanding in recent years will lead to appropriate treatments and therapies targeted to the individual patient in the medium term. They did not give an indication of how many years medium term might be, but the health practitioners interviewed suggested that it takes 15 to 20 years.

Very few large controlled clinical trials for CRPS have been conducted and while there have been a broad range of treatments and interventions proposed, there is a complete lack of high

quality evidence for or against the effectiveness of any CRPS intervention (O'Connell, Wand, McAuley, Marston, & Moseley, 2013). In this absence, Bruehl (2015) suggests that the collective expertise of other clinicians should guide the clinical care of patients. O'Connell and Wand warned that better conduction and reporting of trials using the CONSORT statement utilising a collaborative, multi-centre approach is needed so that practice can be credibly guided in the future. They believe that rigorous investigation is required to confirm interventions that appear promising according to existing data (O'Connell & Wand, 2013). An alternate view is held by Sale and Thielke (2018) who believe that qualitative research is fundamental to evidence based medicine and that the values and preferences of the patient are the foundation of scientific knowledge. As patient reported outcome measures (PROMs) are being embedded into clinical trials, the reductionist model of patient care should become outdated as patient experience becomes more valued as opposed to the orientation of the medical model towards correcting disease and restoring normal functioning (Fuller, 2017; Sarto-Jackson, 2018). Core Outcome Measurement set for complex regional PAin syndrome Clinical sTudies (COMPACT) is a CRPS outcome measurement set devised by an international consortium of researchers, clinicians, patients and industry representatives to facilitate the reporting of outcome measures and capture the severity of CRPS (Grieve et al., 2017). It utilises validated information from PROMs and the CRPS Severity Score (CSS) which was devised by an international group for research purposes and to communicate the clinical status of CRPS patients (Grieve et al., 2017; Harden et al., 2010; Harden et al., 2017).

CRPS is a difficult condition to treat because like other chronic diseases, it is generally incurable and many patients have multiple distinct diseases (Fuller, 2017). Patient care has traditionally been organised around body parts and the whole patient has not been treated in their life context (Fuller, 2017). Guideline directed care is typically disease-specific but CRPS is most likely not a single disease entity, instead, multi-system abnormalities are suspected (Birklein & Schlereth, 2015; Fuller, 2017). Iacobucci (2018) believes that the medical model of care must be challenged and wrote that social factors rather than medical factors drive chronic pain, depression and anxiety. There were many factors involved regarding dealing with the side effects of medication which were captured in the patient interviews.

The participant interviews demonstrated that the side effects of medication were well known by patients but that the effect on the lives of the patient was poorly understood by health professionals. Side effects of medication such as nausea, dizziness, constipation and headaches are recognised in chronic pain research and such side effects are known to correlate to a decrease in quality of life, dissatisfaction with treatment and medication dose changes (Kalso,

2011; Martel et al., 2015). The patient participants elaborated to say that commencement of medication such as Lyrica was associated with weight gain which impacted on their confidence and self-image. As patients were striving to find ways of performing self-care and household tasks and coping with what might be a new 'normal', their clothes did not fit. Costs of new clothing were prohibitive when treatment and transport needed to be paid for. The inability to exercise at pre-CRPS levels also played a part in weight gain. Brain fog was the other major medication side effect noted by patients. Kalso (2011) noted that patients do not like impaired cognitive function due to medication but did not recognise the further effects. Some patient participants told of embarrassment caused by their lack of ability to have meaningful conversations due to concentration and processing issues and stated that tiredness exacerbated their inability to focus which in turn further eroded their confidence. Taking less medication helped the patient to have clearer thoughts but increased pain which led to increased tiredness and more difficulty coping.

Physical therapy and multiple medications are the initial CRPS management strategy but response rates to treatment are quite poor and as one strategy fails, another is added (Goebel, 2013; Russo et al., 2018). Patients can end up believing that "nothing works" but as Russo et al. (2018) suggest some medications might be time sensitive, working during early or later phases of the condition. They also postulate that a multimodal treatment strategy targeting specific activation points may be effective. Surgical options such as spinal cord stimulation was a good choice for some participants, and some had considered amputation. Alternative therapies were common amongst the patient participants. Although there can be high monetary costs involved, there are few side effects considered to be related to massage and meditation, however other therapies such as myofascial treatment were described as very painful. Most patients had tried a multitude of medications and a wide variety of treatment strategies as demonstrated in Table 4. (Refer to table 4 in Chapter 4 Findings, Building an armoury against a moving target). While Binkley (2013), McCabe (2013) and Besa (2015) described patients attempting a myriad of treatments and interventions for CRPS, multiple health practitioner visits and multiple treatment attempts do not seem to be reflected in the fibromyalgia literature (Diviney & Dowling, 2015; Juuso, Skär, Olsson, & Söderberg, 2011). Compared to other chronic pain conditions, management of CRPS involves added complexity (a moving target).

While effective treatments are questioned, so too is the concept of spread. Debate remains in the literature regarding spread with authors such as Schwartzman (2012) stating CRPS affects almost the entire body with the peripheral features of the condition such as hyperalgesia and

inflammation occurring in systemic organs. Harden et al. (2013) believe that spread of the disease is mimicked by secondary proximal myofascial pain. Clinicians report that spread to other limbs is commonly associated with a younger age at onset of CRPS and while it is most commonly contiguous (significant spread of symptoms in the limb originally affected), it can also be ipsilateral or contralateral (Bruehl, 2015; McCabe, 2013; van Rijn et al., 2011). Figures vary regarding the incidence of spread. Goebel (2013) states that the incidence of spread is 7% of patients and that it occurs both with and without further injury. van Rijn et al. (2011) studied the incidence of spread in a clinic specialising in treating CRPS and movement disorders to be 48%. Conversely there is the belief held by Borchers and Gershwin (2017) that the concept of spread has no medical or biologic plausibility. They also believe that the diagnosis of CRPS Type I is implausible and that there are many other diagnoses that would be more reasonable. Type I CRPS is defined as occurring in the absence of definable nerve injury and Type II develops after nerve injury. Schwartzman (2012) believes that many people diagnosed with fibromyalgia have CRPS.

Patient participants were aware that long term CRPS leads to widespread muscle hyperalgesia affecting non-CRPS affected limbs. This was diagnosed as central sensitisation, fibromyalgia, or was interpreted as spread by both patients and HPs. The mechanics of central sensitisation are not completely understood but may explain continued hyperalgesia, allodynia and chronic CRPS pain (Reinersmann et al., 2013). Problems arise for patients when they develop new symptoms. For example, someone with upper limb CRPS may develop a sore foot and have thoughts such as - Is it plantar fasciitis? Is it spread? Do I go to the doctor? Should I just ignore it as part of CRPS? What if it's broken? These thoughts are often labelled as catastrophising by HPs, but they are legitimate thoughts for patients debating potential actions to take. The HP responses to such issues vary depending on their level of CRPS expertise and their stance on many CRPS questions posed in the literature. The mechanics of CRPS are not completely understood and therefore targeted therapeutic interventions and explanations to patients are not uniform (Reinersmann et al., 2013). Treatment of patients is determined by the HP level of CRPS knowledge and their reaction to questions such as the existence of spread, CRPS Type I as distinct from Type II, the idea that Type I and Type II is obsolete or that there are subtypes of CRPS, classification of CRPS as a neuropathic pain condition, an autoimmune condition or a maladaptive inflammatory response (Borchers & Gershwin, 2014; Bruehl, 2015; Dirckx et al., 2015; Schwartzman, 2012; van der Veen, 2015). The chronic CRPS patient requires a longer time in consultation with their healthcare practitioner than is usual in a time-poor clinical

setting and this also impacts on the therapeutic care pathway implemented by the HP (McCabe, 2013).

The discrepancy between HPs' understanding of the disease was reflected in the inconsistency between treatments offered to patients, particularly opioid medication. One of the biggest current issues in pain management is the use of opioids or lack of opioid analgesics being prescribed to patients. WHO (2000) describes the lack of adequate pain relief in cancer patients as "tragic" yet considering that CRPS pain is rated higher than cancer pain on the McGill Pain Scale (Tahmouh, 1981), WHO does not appear to have a position regarding undertreatment of CRPS. It has been recognised that moderate to severe pain requires opioid analgesics for treatment, however, in many countries, concerns and policies focus on preventing addiction or dependence (WHO, 2000).

It is not within the realms of this research to provide in-depth discussion about the risk of addiction or dependence, however it is for this reason that IASP (2018) recommends alternatives to opioids must be found for all chronic pain. Some participants described adverse attitudes to opioids by health care providers while others told of contrasting opinions encountered regarding their use of opioids. Recent moves to comprehend the use of opioids in chronic pain such as the Queensland Clinical Senate Workshop 'Managing the pain of opioids' held in July 2018 are a start to addressing some these issues experienced by patients.

BATTLES WITHIN THE WAR

The discussion to this point has covered the difficulty experienced by patients in receiving appropriate treatment and some of the reasons for this. The next theme to be discussed sits at the bottom right of Figure 2. Each aspect of living with CRPS can be thought of in terms of separate, or parts of a battle and in this instance, CRPS is the war. There are many battles patients face on a daily basis and there are varied approaches to these battles described in the literature. Health practitioners rarely consider how much people battle to live with this disease and the difficulty of working out the balance of moving to improve or maintain function while not causing a pain flare.

Leaving the house was a major issue in itself for some participants who described extreme pain and lethargy the day after using too much energy performing activities. People who previously led physically active lifestyles were forced to accept less from their bodies. It is well known that sleep quality can be improved in the general population by increasing daytime exercise or physical activity but it has been shown that high fluctuations in activity and high-intensity activity correlates to poor night-time sleep in the chronic pain population (Andrews, Strong,

Meredith, & D'Arrigo, 2014). Pain increases during and after therapy are usually caused by an overactive protective system rather than actual damage and there are arguments supporting the notion that attending to pain can increase pain itself (Lotze & Moseley, 2015). The concept that pain does not equal damage and that people should move despite pain (Lotze & Moseley, 2015) is difficult to appreciate when you are the person experiencing pain.

Activity pacing, a strategy used in pain management which involves adjusting the speed at which activities are conducted and includes taking breaks and goal setting (Antcliff et al., 2018), was described as difficult by most participants. Patients find it difficult to not overdo things on days they are feeling well and consequently often 'suffer' the day after being particularly active. Kinesiophobia, an irrational debilitating fear of physical movement, was described by many participants, at least in the early stages of their condition but has been found to not contribute to functional limitations in people with chronic CRPS in the legs (Marinus et al., 2013). Pain intensity and the amount of resting used as a pain coping strategy was found to limit activity and participation in a study conducted by Marinus et al. (2013) and they indicate that adequate pain treatment and physiotherapy are an important treatment approach. Some participants described unconscious safety-seeking behaviours such as altered movement patterns which led to muscle strain and pain in other parts of the body. Some participants felt they had to protect the limb, but immobilisation and non-use of the affected limb by those participants led to swelling, contractions, atrophy and deconditioning.

Hausteiner-Wiehle and Henningsen (2018) suggest that a maladaptive protective response contributes to CRPS pathophysiology, and Punt, Cooper, Hey, and Johnson (2013) along with Bruehl (2015) believe that pain or fear of future pain exacerbations is critical in the development of neglect-like symptoms in CRPS patients. Those patients who could not find adequate relief described major problems in moving and using the affected limb.

Conventional pain treatment (relieving pain with medication or exercise) and pain management (encouraging patients to live with their pain) are being combined with other strategies to form pain rehabilitation (Lotze & Moseley, 2015). Termed the 'four pillars of intervention', UK therapeutic guidelines align with this approach and extend the IASP algorithm of care so that patients are educated to change their meanings of pain from being a sign of damage to a protective strategy in an overly protective body which can be managed when combined with pain relief, psychological support and physical rehabilitation (Goebel, 2013; McCabe, 2013; Smedley, Coulson, Gavin, Rodham, & Watts, 2015). The clinician-patient relationship is vital in this process and is critical to patient optimisation of quality of life despite living in constant pain (Lotze & Moseley, 2015; McCabe, 2013).

Many authors recognise that chronic CRPS is associated with a low Quality of Life (QoL) score, serious impairments to functioning and activities of daily living and in extreme cases, can have devastating consequences for patients such as impaired cognitive function, atypical chest pain, increased sweating, poor perfusion to the lower extremities and constipation (Bruehl, 2015; Goebel, 2013; McCabe, 2013). van Velzen et al. (2014) concluded that the quality of life (QoL) in people with CRPS is lower than patients with other chronic pain conditions mainly due to reduced physical health. The impact on physical health is greater for CRPS patients with a lower limb affected, or multiple affected limbs, than those with an upper limb affected (van Velzen et al., 2014). Studies have shown that there are many benefits related to relieving pain including increased activity of daily living, better sleep, better functioning, increased ability to work, and an overall improvement in QoL (Moore, 2013). Many patients with long-standing CRPS who have received the most up-to date management and interventions will not experience pain relief although a 50% pain reduction was reported in 50% of patients receiving a spinal cord stimulator (SCS) (Goebel, 2013). However, there was no functional gain and repeat surgery is required in up to a third of patients undergoing SCS treatment (Goebel, 2013). Efficacy of a SCS five years after implantation is suspected to be no greater than physical therapy alone (Bruehl, 2015).

According to the patient interview participants, health practitioners, besides not understanding the effect of systemic complications, had little understanding of the impact that being unable to complete household chores had on their lives. Being unable to complete their traditional roles of cooking and cleaning left some women feeling guilty that their husbands had an increased workload. Those participants with lower limb involvement had more mobility issues than those with upper limb issues which affected their gender roles. Men stated that being unable to mow the lawn affected their self-image and both men and women reported feeling guilty when being unable to fulfil their parenting roles. Disruption to family role is known to be problematic in people living with other chronic pain conditions such as low back pain and fibromyalgia (De Souza & Frank, 2011; Juuso et al., 2011; Robinson, Kennedy, & Harmon, 2013). Loss is also commonly reported in chronic pain research and in this research it was often closely related to guilt and participants felt they had lost friends, jobs, mobility and their former fully functioning body (De Souza & Frank, 2011; Newton, Southall, Raphael, Ashford, & LeMarchand, 2013; Robinson et al., 2013). Those patients who had insurance claims refused also felt a loss of credibility which impacted relationships within their families. The interviews revealed that financial considerations were not only related to loss of jobs and insurance claims, but also to high costs of treatment and medication, and often impacted on

the finances of the family. Some young adults became dependent on their families and others became dependent on disability pensions. Government and insurance company employees, who assessed the patients' claims, had little knowledge of CRPS and this had major implications on the ability of the patient to access disability support or to negotiate insurance claims. CRPS is resource intensive for both health and social care and McCabe (2013) suggests that economic evaluation is required along with health evaluation to ensure that potentially expensive specialist resources are utilised appropriately. Education of insurance and government workers was suggested by patient participants as the best way to ensure they could lessen the judgement expressed by people who they went to for help.

Most participants had consulted a physiotherapist at some stage, but the participants expressed a diverse range of attitudes to the practitioners. The particularly unhelpful HPs were discussed by patient participants more often than positive encounters with them. Countless examples can be found in the literature demonstrating unhelpful attitudes to chronic pain such as Francis (2015), who believes that pain without organic origin is a fetish; a means to gratification and satisfaction to make up for loss or trauma in earlier life commencing with the first emotional experience – birth. The recently published study by Llewellyn, McCabe, et al. (2018) stated that “the frequency that: ‘generalised pain and discomfort’ was identified by patients with CRPS was unanticipated” (p. 561). Statements such as these examples may explain the belief patients have that people who have never been diagnosed with CRPS have little understanding what it's like. Llewellyn, McCabe, et al. (2018) also stated that “we are mindful that our study was reliant on self-report of symptoms, which were not clinically verified and that this may be considered a study limitation” (p. 562). The use of the aforementioned COMPACT tool will lessen such research limitations.

Judgemental attitudes from health professionals also impacted the reported effects of loss and guilt on the patient participants. Those mourning such losses often felt unsupported by their HP. Health professionals often forget to talk to patients about how and why they feel because they prioritise medical aspects of care and critical illness such as heart disease over chronic pain which is more difficult to adequately manage (Hansson et al., 2016). Those patients who had lost mobility reported unhelpful comments from HPs regarding the use of crutches or wheelchairs sourced by the patient in an attempt to move around more easily. Patients in this study who had lower limb CRPS had more mobility complications than those with upper limb involvement and they linked their use of crutches to carpal tunnel or upper limb spread which was sometimes questioned by the HP. The most unhelpful comments patients received were those criticising their use of medication, particularly opiates and accusations of drug seeking

behaviour. This occurrence in the hospital setting during a ketamine infusion demonstrates a lack of understanding, lack of compassion and lack of empathy besides a lack of knowledge in the HPs who made the statements. Hansson et al. (2016) suggest that health professionals require support to manage the competing demands of high workloads and patient needs and in order to see the person behind the pain, they need to adopt a caring and empathetic approach to patients in pain and enter into meaningful conversations about meanings of living with chronic pain.

DEVELOPING BATTLE PLANS WITH ALLIES

When considering patients are faced with attitudes such as those described above, it is no wonder many find themselves advocating for better treatment from their healthcare providers. Patients look for people who can help them navigate life with CRPS. Such allies may or may not be friends, family members or healthcare professionals. The word ally is used because patients should be on an equal footing, in partnership with those providing care. Each side needs to respect and understand the views of the other, but this does not always happen particularly within the patient-doctor relationship. Overtones of HPs not respecting the thoughts of the patient were evident in the interviews, but patients accessing a multidisciplinary clinic were more likely to praise the treatment they received.

Multidisciplinary pain management including specialised physiotherapy, occupational therapy and psychological/behavioural treatments have long been recommended in the CRPS literature although despite positive anecdotal evidence, techniques such as cognitive behavioural therapy are not universally recommended due to the low numbers of patients and limited numbers of trials conducted (Goebel, 2011; Harden et al., 2013; O'Connell et al., 2013). This theme sits on the bottom left of Figure 2 (Refer to Figure 2).

Unfortunately, some patients do not have access to adequate care from a multidisciplinary clinic or healthcare professional. In this instance patients usually turn to each other for advice on what doctor, or what clinic provides the best care. This was one of the most lauded benefits of the internet and support groups in the interviews. Waiting lists to see a specialist are usually long whether it's a public or private service, and there is a cost involved when accessing private services, but the interviews showed that patients are prepared to pay anything or travel great distances (including to other countries) to access better care or treatment. Those patients who could not afford private care were forced to advocate for another doctor within the service which they found frustrating and stressful as they felt they had no control. Control appears to be important for patients' ability to self-manage rather than feeling that CRPS controls them (Smedley et al., 2015). Low levels of perceived control is thought to lead to

unhelpful coping responses such as avoidance of the feared situation (Lauder, McCabe, Rodham, & Norris, 2011). This is true of the interview participants as some patients in this situation stopped attending the unhelpful doctor. The increased pain and deterioration that resulted from this decision caused disability and those patient participants in this situation all expressed feelings of helplessness. When patients couldn't find support within the healthcare system they looked for extra support from their families.

Family support was held in high regard although many participants felt guilty due to the extra work they caused for family members. Those participants who felt they had good support systems including family, friends and HPs appeared to be coping with their condition better than those who did not. HPs agreed that support systems were necessary but also thought attributes such as flexible thinking and resilience were important for patients to cope with their disease because they are more able to accept the changeability of the condition. Those families who could apply flexible thinking created practical solutions to everyday problems. The example Carolyn gave about family members walking on her affected side when in crowds gave her the confidence required to go out without the fear of being bumped and causing a flare. Taking on some of the responsibility of CRPS such as avoiding contact with the affected limb is termed 'shared vigilance' by Lauder et al. (2011). They claim that involving the support person in rehabilitation activities is likely to have positive outcomes for the person with CRPS.

People without strong support (and therefore little or no shared vigilance) can find themselves becoming socially isolated and withdrawn according to Smedley et al. (2015). The interview participants who sought support from online communities found information and friendship forthcoming from the shared experiences. Others voiced concern that the amount of negative experiences posted online negated the positive aspects of internet interaction. The internet often served to cause distress rather than being a source of support and information. CRPS websites are also known to catastrophise the condition and worst-case scenarios are more prevalent than people finding cures or achieving remission (Rodham et al., 2009). Research has shown however that social support via the internet can play a role in education, pain relief, rehabilitation and psychological intervention in people with CRPS and they are tolerant of knowledge deficits amongst others (Lauder et al., 2011; Smedley et al., 2015). Research has also shown that people are less tolerant of healthcare professionals who do not understand CRPS (Lauder et al., 2011). Interview participants had little patience for those HPs who did not ask before touching an affected limb, who did not respect the patient as an individual and for those who wanted detailed descriptions or numerical values of the extent of their pain.

WARRIOR OR PRISONER OF WAR

It is well documented that the experience of pain can be influenced by the beliefs and expectations of the person experiencing it (Lotze & Moseley, 2015; van Vliet, Meulders, Vancleef, & Vlaeyen, 2018). Those patients who exhibit pain related fear and subsequent avoidance behaviours are generally more anxious than those who do not exhibit pain related fear (van Vliet et al., 2018). The facts that the first diagnostic criteria for CRPS is pain disproportionate to any inciting event and that acute pain is a warning for the body that something is wrong, seem to be at odds with each other when CRPS is first developing (Birklein & Dimova, 2017; Nicholas, Molloy, Tonkin, & Beeston, 2000). The interviews revealed that some patient participants suffered immensely as if a prisoner of the war of CRPS while others managed to find the mental strength and resilience to fight it, becoming a warrior. The methods used by patients to confront their problems varied considerably with some people actively addressing issues and others hiding from the world, and some ranging in between these two extremes.

The term warrior is often found on CRPS internet sites and the health practitioners interviewed expressed acceptance of this term as appropriate. Factors they thought necessary to create a warrior mentality were mental strength, resilience and access to health practitioners with CRPS expertise, particularly psychological support. Patients agreed but also thought it was a personal quality within themselves. At times, patients attempted to project better health than they felt.

A recent study examined the effect of acute pain on facial expressions (Karos, Meulders, & Goubert, 2018). They deduced that reduced pain expression might be the norm, particularly when the patient feels threatened which in turn increased the chance of pain underestimation which is common in clinical practice. It has also been suggested that CRPS patients consider pain to be their normal state and only report pain that goes beyond that level (Llewellyn, Birklein, et al., 2018). Patients in this research either hid their pain from friends and loved ones so as not to worry them, or as an attempt to fit in with others and not draw attention to themselves. Lauder et al. (2011) found that people with CRPS have competing needs to hide their pain and have it acknowledged and validated by friends and family. This concept was reflected in this research by participants who found a way to live with pain and also live as close to their normal life as possible. This involved making the best of the situation and finding novel solutions to problems. Patient interviews also highlighted that their goals were not necessarily the same as those of the HPs and there seems to be a disconnect in the ideals of each group.

Levels of CRPS knowledge was examined by Brunner, Gymesi, Kissling, and Bachman (2010) who concluded that patients' knowledge of CRPS rarely met the minimum medical knowledge as defined by experts which affected their ability to self-manage. The questions asked related to specific medical terminology and pathophysiology and included a question which asked "what is the main goal in the treatment of CRPS? The correct answer to this question was deemed functional restoration and pain reduction. Although questions were asked regarding patient views they were not asked what their goals were. The question was posed however "on what topics would you like to get more information? It was answered "therapy and general aspects of the condition". Further research has been performed asking patients what advice they would give other patients (Rodham, McCabe, Pilkington, & Regan, 2012) and what they consider cure to be (Llewellyn, McCabe, et al., 2018) which indicates that the patients' perspectives are beginning to be considered important within the CRPS research community.

Not all perspectives are agreed upon, however. The patient interviews in this research revealed that they wanted to spread awareness of CRPS in the hope that the general community would be more accepting of their condition. Friends, family, and co-workers for example with a good understanding of CRPS were thought to understand the changing symptoms and acknowledge when the patient could not do as much and required extra support or rest. Campaigns such as Colour the World Orange where well-known landmarks throughout the world are lit in orange light, and personal blogs were amongst strategies used by patients to spread awareness. HPs thought education of other health professionals was of more importance because this would be more likely to result in quicker diagnosis. Patients suggested attending clinical education sessions and some of the HPs indicated support for this idea.

Although CRPS has been shown to not have psychologic origins (Feliu & Edwards, 2010), some of the patient participants displayed signs of poor coping and some admitted to diagnoses of depression subsequent to their CRPS diagnosis. Upon hearing the stories of some of the participants, some of the HPs interviewed felt there were tones of catastrophising. Patient participants did not recognise that quality within themselves, however, many said that there are examples of catastrophising in the CRPS websites. Patient participants did however recognise times of poor coping behaviour, describing times of being unable to function properly.

Health care providers can assist patients to develop a strong sense of coherence which affects the choice of coping strategies used by people to cope with chronic illness resulting in a positive mental effect on QoL (Harden et al., 2013; Kristofferzon, Engström, & Nilsson, 2018).

van Velzen et al. (2014) studied 39 people with CRPS and found that patients often have risk factors for suicidal ideation such as severe pain, depressive symptoms, and decreased functioning and conclude that treatment of CRPS should include psychiatric evaluation and treatment. Racine (2017) proposed that all chronic pain patients, regardless of type, are at risk and should be assessed for suicidality. HPs were divided in their reactions to the notion that CRPS is nicknamed the suicide disease, from being unaware to not being surprised. Patient participants did not disclose suicide attempts, but some admitted to considering it and making plans for the future. The value of psychological support was reiterated by many participants.

Psychological support was acknowledged as important by the health professionals but some of the other problems patients considered common are rarely taken into consideration by health professionals. One example of this is trophic changes to hair, nails and skin which are part of the Budapest diagnostic criteria (Birklein & Dimova, 2017). (Refer to Table 1 Budapest diagnostic criteria for CRPS in Chapter 1 Introduction – What is complex regional pain syndrome?). The meaning and effects of these changes, particularly brittle fingernails can be a major issue for men with CRPS as they are unlikely to apply gel or acrylic nails to strengthen fingernails which is generally acceptable only to women. Allodynia affects both males and females but can cause an inability to tolerate a bra. This often impacts significantly on a woman's life in regard to being braless in public. Being unable to cope with buttons or zips forces patients to wear simple dresses or pull up pants such as tracksuits. Women in particular had self-esteem issues related to not being able to blow dry their hair, wear nice clothes or wear make-up. Self-care activities were the most difficult activities described. When having a shower feels like needles hitting the skin, some participants did not shower every day, while others developed trust issues because they couldn't guarantee their carer would take due care to not hurt them.

SUMMARY

Little is known about the exact mechanism of CRPS and considering that even the definition of pain is currently debated (Cohen, Quintner, & van Rysewyk, 2018; Treede, 2018), it is no wonder patients struggle to live with the condition. Chapter 4 presented the findings, and this discussion has described the essence of living with CRPS as a daily battle. People living with other chronic pain conditions face some of the same issues, but there are many battles that are unique to CRPS. For example, other conditions are not known to spread to other limbs or to organs. Such issues are difficult to understand not only for the patient, but also for health professionals because, spread, like the extreme, continuous pain, seems implausible. Due to

the lack of knowledge about the specific pathophysiology of the condition, there is currently no known treatment or cure, and patients must change their lifestyles to adapt to living with limitations caused by CRPS.

Research findings have been discussed thematically and comparisons to research literature have been made. Those patients who have good support systems in place and have access to health practitioners with a high level of expertise regarding CRPS were more likely to become warriors as opposed to prisoners of war. Education of the patient and the HP plays a major role in the ability to live or to assist a patient to live with the condition. Limitations will now be recognised and recommendations for future research and future management will be proposed.

LIMITATIONS

The work of Guba and Lincoln (1989) provided researchers with a response to the criticism that qualitative research was subjective, biased and untrustworthy. They suggested strategies to ensure rigour; credibility, dependability, trustworthiness, and transferability. An approach to ensuring rigour within heuristic hermeneutic phenomenology was outlined by Johnston et al. (2017), and it is these methodological considerations and those by Letts et al. (2007) which have been followed in this research (Refer to Chapter 3, Methodology and methods, Publication and Trustworthiness for further information). Multiple strategies were utilised in this research to improve rigour. Participants were sourced from different countries. There was a range of experiences and length of time living with the condition. Three participants developed the condition as children and the age range of participants spanned 39 years. There was also a mix of males and females. The fact that multiple sources, health professionals and patients, were interviewed increases the credibility. Health practitioners and participants repeating the same information, and participants relaying similar stories demonstrates confirmability. These findings, however, can be taken to be transferable only to the populations represented by the participants.

As there was a reliance on word of mouth and snowballing to access people who have not joined a support group or who do not engage with the internet, some people living with CRPS were not given an opportunity to participate. It was considered inappropriate to access closed Facebook sites for research purposes which restricted data collection from those who are at opposite ends of the disease continuum. Although the research was advertised broadly, I was unable to interview people who are totally reliant on others to care for them and also was unable to interview those who consider themselves cured or in remission. Advertising either

did not reach these groups of people, or they were unwilling to participate. Although there was a symptom range of four months to 18 years in the patients interviewed, the inclusion of these groups of people may have increased the depth of being able to relate a more complete lived experience of CRPS. Children were also not interviewed, and their experience may be different to adults.

Within the sample of the 17 participants from Australia, Singapore, USA, England and Wales, experiences were recurrent, and participants largely echoed each other when telling of their experiences. However, all participants were white Anglo-Saxons and living in 1st world countries with similar health care systems and access to health professionals. If participants were sourced from other countries such as developing countries, or from other cultures such as indigenous Eskimo, Central European or African, the data may have led to alternate themes emerging.

One of the main criticisms of qualitative research is bias and inability of the researcher to remain objective (Kahn, 2000; Levasseur, 2003). The role of the researcher in qualitative research can have implications on influencing the findings (Letts et al., 2007). Data from the experience of the researcher was used in this study. Assumptions and biases were made apparent and the research followed the suggestions made by Johnston et al. (2017) to ensure rigour when using data from the experience of the researcher. Quotes were included in the Findings chapter to allow the reader to audit the theme.

FUTURE RESEARCH

During this research I found aspects of life with CRPS that I wasn't able to explore, but which could be looked at further. Qualitative research commencing with those who consider themselves cured or in remission, and those who consider themselves with full body CRPS and are completely reliant on care from others is required to gain a complete picture of living with CRPS. Children, the elderly and people living in countries and from cultures other than those accessed in this research could also be interviewed. Most people in this study had CRPS first suggested to them by a physiotherapist and future research to determine which health professional is most likely to diagnose CRPS may help to determine specific HP education requirements. The same demographic accessed in this research could be utilised for further CRPS research and research questions which might be posed are:

- What is the relationship between the limb affected by CRPS and the experience of living with the condition and quality of life?
- What is the rate of suicide or suicide ideation in the CRPS population compared to the general chronic pain population?
- How can patients build resilience after CRPS diagnosis?
- What is the incidence of CRPS in Australia/World?
- How do women diagnosed with CRPS decide if pregnancy is appropriate for them?
- Would a weight loss program which delivers premade food to the door assist those patients who are overweight and unable to cook for themselves to lose weight and gain better mobility? Does this help with pain control and quality of life?

The majority of these questions are qualitative. Quantitative research can assess the effectiveness of medications or treatment regimens but qualitative research can explore attitudes and beliefs and determine how and under what circumstances, individuals might adhere to these regimes, because patient preferences and values should be an equal part of evidence based medicine (Sale & Thielke, 2018). Gaining a greater understanding of the factors affecting the quality of life of patients can help health professionals to understand the influences on health and illness experiences and therefore provide compassionate person centred care (Gelling, 2015).

FUTURE OUTPUTS FROM THIS RESEARCH

Articles providing the findings of this research are in the process of being written and reviewed. They will be submitted to PAIN, Pain Medicine or Journal of Pain for publication. I have been invited to write a book chapter for the Meanings of Pain Volume II which will use data from this research to discuss the meaning of living with CRPS. Findings of this research will be sent to all patient and HP participants. It will also be converted to lay language for ease of understanding and will be disseminated to patient participants, pain support groups and CRPS specific groups. My ultimate goal is to write a book for people living with CRPS. I hope that with publication of an inexpensive guidebook, the questions I had upon being diagnosed will be answered for others diagnosed with this condition.

CONTRIBUTIONS OF THIS RESEARCH

The contributions of this research to knowledge, theory, methodology, practice and policy will now be described.

KNOWLEDGE

This research provides better understanding of the experience of living with CRPS which is hoped to increase understanding and empathy in health practitioners and provide a reliable information source for patients. Publications that address an identified gap in the pain literature have been cited and new publications are currently being written or are under review. The planned lay information and book will provide practical information that can be used by individuals affected by CRPS, their families and their health care providers.

THEORY

A model of lived experience of chronic pain was proposed in the published literature review (Johnston et al., 2015). Demonstrating that people living with chronic pain find acceptance in dealing with challenges through being informed and coming to terms with the loss of their former pain-free body and way of life. It posed the question of where does the person living with CRPS fit? This research found that people living with CRPS have similar experiences to those living with other chronic pain conditions but experience additional challenges. It demonstrated that the essence of living with CRPS is a battle and five themes were revealed which are depicted in Figure 2 (Refer to Figure 2).

METHODOLOGY

My contribution to methodology is my paper on using my own data within phenomenology. It is argued that in hermeneutic phenomenology the researcher must make their preconceptions explicit and that bracketing is not possible (Gelling, 2015; Levasseur, 2003). Using data from my own experience in this research assisted me to identify both conscious and sub-conscious biases and preconceptions and allowed for my experience to be another data source. It aided in the recruitment and rapport building with the patient participants which may not have been otherwise possible to the same extent. Qualitative research is not considered to be part of evidence-based medicine and is often ascribed low level evidence and is not often recommended to inform practice or policy (Sale & Thielke, 2018; van Wijngaarden, Meide, & Dahlberg, 2017). Arguments to consider the uniqueness of each individual person and to value knowledge of the lifeworld as essential is gaining momentum in the published literature as qualitative evidence is increasingly considered fundamental and indispensable for practice and policy (Florczak, 2017; Gelling, 2015; Sale & Thielke, 2018; van Wijngaarden et al., 2017).

PRACTICE

If my recommendations are followed, practice will change to be more aligned with the outcomes patients want rather than being medically dictated. Patients will be referred to

specialists and will receive a diagnosis in a timelier manner. Health practitioner education is needed at the undergraduate level and ideally, chronic pain will no longer be grouped with acute pain but will be taught and treated as its own entity. It is acknowledged that specific CRPS education is not required at undergraduate level except to physiotherapists and occupational therapists, as the majority of HPs are unlikely to encounter the condition during their entire career. Postgraduate and clinical education of HPs working in areas such as fracture clinics, orthopaedics, general practice and pain clinics should include CRPS education and emphasis should be placed on the referral to a specialist of any patient the HP is unable to diagnose and any patient demonstrating pain disproportionate to the inciting event. Patients will receive a timely diagnosis and specific CRPS education including the fact that it can go into remission.

POLICY

My findings will go to support groups for inclusion in submissions to government departments. My membership of a pain education focus group through the State-wide Persistent Pain Clinical Network and Clinical Senate on Opioids have resulted in my voice being heard by the Queensland Government already.

RECOMMENDATIONS

Although generalisation is not an aim of phenomenology (Crotty, 1996), it illuminates the essence of the phenomenon and the general structure of meaning which is a commonality through the experiences of each participant (van Wijngaarden et al., 2017). The essence of living with CRPS is a battle and the in-depth understanding brought about by the wide breadth of interview participants in this research who reported similar information, and supporting literature renders it possible to make some recommendations based on the findings of this research (Florczak, 2017). Figures 2 and 3 provide a graphic illustration of the lifeworld of CRPS. This lifeworld must be understood by others, especially healthcare professionals if people with CRPS are to be given appropriate patient centred care which is focused on each individual patient. Further recommendations are now provided:

EDUCATION OF HEALTH CARE PROVIDERS

All HPs should be educated about long term chronic pain and it is recognised that pain networks such as IASP and the Queensland State-wide Persistent Pain Clinical Network Education Focus Group are currently working to improve the quality, safety, and effectiveness of persistent pain management education. It has been proposed that patient-centred interprofessional pain education results in effective collaborative practice and quality health

outcomes (D. B. Gordon, Watt-Watson, & Hogans, 2018). Within the context of education about CRPS, the following points are recommended for consideration:

Teach acute and chronic pain as distinct topics.

The incommunicability of chronic pain places pressure on patients to describe it adequately and it is often incomprehensible to others, particularly health care providers (Ashe et al., 2017). Poor treatment by health care professionals due to the incongruence of pain expression compared to pain verbalisation was a finding in this research and this is presumed to be largely a problem due to inadequate pain education. Chronic pain must be taught separately to acute pain because they are different. A textbook for nursing students (for example) acknowledges that there are rarely overt behavioural responses when pain is chronic but contrastingly, also states that pain assessment consists of two components: a pain history and; direct observation of behaviour (Applegarth & Flenady, 2018). Direct observation is more relevant to a patient with acute pain. Studies have shown that people will suppress their expression of pain when they do not feel safe (Karos et al., 2018) and will “put on a mask” as Laura described it so as not to worry friends and family.

Stop rating chronic pain without context

Patient participants discussed difficulty defining pain numerically without giving it context, yet clinicians seem to have a need to quantify pain believing that they must be able to measure pain in order to understand and treat it (Turk & Melzack, 2014). Pain measurement using visual analogue scales, numerical rating scales or verbal rating scales have been utilised in the past but capture a unidimensional experience and are best used to rate acute pain (Bendinger & Plunkett, 2016; Katz & Melzack, 2014). A pain score of 2 or 3 is debilitating when it's continuous but an analogue scale does not reflect this. The McGill Pain Questionnaire (MPQ) and the Short-Form McGill Pain Questionnaire (SF-MPQ) are considered to be the gold standard in measuring aspects of pain such as quality, intensity and duration and the Short-Form McGill Pain Questionnaire – 2 (SF-MPQ-2) has been developed to measure the qualities of both neuropathic and non-neuropathic pain (Katz & Melzack, 2014). The MPQ and SF-MPQ-2 therefore would be better tools to use with CRPS patients to provide information regarding the sensory, motivational and cognitive dimensions of their chronic pain (Bendinger & Plunkett, 2016).

Include patients as educators

The value of the patient experience in pain education has been recognised by the IASP with the publication of an e-book designed to stimulate HPs to think about what it is like to live with

pain (Toye et al., 2018). People with CRPS are keen to spread awareness and health professionals stated that talks by patients can provoke powerful learning opportunities and are more likely to be remembered. The inclusion of patient presentations at university, in-service/training days in clinical areas, and at conferences could help improve clinical care through better understanding of the experience.

EDUCATION OF PATIENTS

Education is required for patients, caregivers, family, and workplaces and extended support networks. The value of positive family support in helping the CRPS patient has been acknowledged and suggestions have been made that support people be included in CRPS education (Harden et al., 2013; Lauder et al., 2011; Rodham et al., 2009).

CRPS specific education at pain clinics

Although sharing some characteristics with fibromyalgia, CRPS is different to other chronic pain conditions and pain education to CRPS patients needs to acknowledge these points of difference.

Availability of research findings

Lay versions of published articles should be made available for patients.

TREATMENT

Psychological support as a standard treatment

Multidisciplinary teams are increasingly suggested as the optimal treatment model for people with CRPS (Feliu & Edwards, 2010; Harden et al., 2013). Given the data to emerge from the warrior or prisoner of war theme it would appear that the inclusion of a psychologist or psychiatrist is mandatory to assess and aid or further develop the sense of coherence and resilience factors in all patients. Referral to a rheumatologist and/or neurologist may also be considered to ensure diagnosis and management of coexisting symptoms outside the scope of the pain management physician.

Multidisciplinary team members

The multidisciplinary team members should include the following:

- Pain management physician
- Nurse practitioner
- Physiotherapist
- Occupational therapist

- Exercise physiologist
- Massage therapist
- Psychiatrist/psychologist
- Dietician
- Social worker – to help with financial issues
- Pharmacist

CONCLUSION

This research evolved from my inability to find information about living with a diagnosis of Complex Regional Pain Syndrome, a chronic incurable pain condition. As has been shown, people with CRPS live with the same problems of a person with a general chronic pain condition and have added difficulties which are mostly unique to CRPS. The extra burden of living with CRPS is due to its rareness, the unknown aetiology of the condition, the unpredictable pathogenesis, and the lack of effective treatments available. Research continues across the world to learn more about the condition and qualitative CRPS research is gaining in popularity. However, as far as I am aware, this is the first study using a phenomenological approach to uncover the essence of living with CRPS. The aim of this research was to understand the phenomenon of chronic pain in the lifeworld of people living with CRPS. The research question was: What is the experience of living with chronic pain in the lifeworld of CRPS? The answer is – it is a battle.

This research suggests that people living with CRPS experience the problems of disbelief, loss, coping with a non-compliant, constant painful body, self-management and alleviating pain and finding treatment as experienced by people with a general chronic pain condition. This project highlighted that CRPS patients also have issues specific to the disease such as difficulty getting a diagnosis, the lack of CRPS knowledge of health practitioners and in the general community leading to difficulty accessing expert care and support. Most CRPS research is quantitative and those health professionals who are aware of CRPS do not understand the experience of the patient living with the condition. The fact there is no definite treatment impacts patients and their families yet little qualitative research has been conducted on the CRPS affected population so far. The voice of the patient is extremely valuable in research about chronic pain which justifies why a qualitative approach was taken with this research. The choice of phenomenology as the methodology and method is a valuable one if the researcher explicates preunderstandings and assumptions - an important first step in performing phenomenological research.

The overarching essence of living with CRPS was identified as a battle. Within the battle, there were five major themes: dealing with an unknown enemy, building an armoury against a moving target, battles within the war, developing battle plans with allies, and warrior or prisoner of war. The research findings suggest that health practitioners have limited understanding of the big and smaller battles faced by patients such as fingernail problems, fear of being touched without warning, mobility and the fear of spread indicated by pain in other parts of the body. Patients require support in many aspects of their lives. Improving the health literacy of patients, especially their pain literacy, will help the CRPS affected cohort to understand their condition and begin to accept their new normal.

Education about pain and specifically about CRPS would alleviate some of the distress caused by accessing misinformation and catastrophising posts found online. Finally, it was identified that patients' goals are not necessarily the same as those of the health professional. Patients believe that raising awareness will help with support and understanding from the general community. HPs believe that increased awareness of other health professionals will aid in faster and more accurate diagnosis. While both are correct, the needs of the patient must be paramount.

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APPENDIX A. Ethics documents for patient interviews

A.1 HREC APPROVAL LETTER



University of the
Sunshine Coast

28 March 2014

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Acting Manager, Office of Research
Tel: +61 7 5459 4574
Email: humanethics@usc.edu.au

F21825

Ms Colleen Johnston
Prof Marion Gray
Dr Florin Oprea
Dr Bill Allen
University of the Sunshine Coast

Dear Colleen, Marion, Florin and Bill

Expedited ethics approval for research project: Understanding the lived experience of Complex Regional Pain Syndrome (CRPS) in Australia (S/13/577)

This letter is to confirm that on 25 March 2014, following review of the application for ethics approval of the research project, *Understanding the lived experience of Complex Regional Pain Syndrome (CRPS) in Australia*, the Chairperson of the Human Research Ethics Committee of the University of the Sunshine Coast granted expedited ethics approval for the project, subject to specific conditions which have now all been satisfied.

The Human Research Ethics Committee will review the Chairperson's grant of approval and the conditions of approval at its next meeting and, should there be any variation of the conditions of approval, you will be informed as soon as practicable.

The period of ethics approval is from 28 March 2014 to 22 August 2016. Could you please note that the ethics approval number for the project is HREC: S/13/577. This number should be quoted in your Research Project Information Sheet and in any written communication when you are recruiting participants.

The standard conditions of ethics approval are listed overleaf. If you have any queries in relation to this ethics approval or if you require further information please contact a Research Ethics Officer by email at humanethics@usc.edu.au or by telephone on +61 7 5459 4574 or 5430 2823. I wish you well with the success of your project.

Yours sincerely

Kelly Stewart
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STANDARD CONDITIONS OF ETHICS APPROVAL

The standard conditions of approval for all human research projects are the following:

1. Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.
2. Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Chairperson of the Human Research Ethics Committee by no later than the next working day after recognition of an adverse occurrence/event.
3. Provide the Committee with a written Annual Report on the research project by 28 March 2015 and on completion of the project on 22 August 2016 using the proforma "Annual / Final Report on Approved Research Project Involving Humans". This may be accessed on the University of the Sunshine Coast portal at: Research and Research Training>Research Ethics>Human Research Ethics>Forms> Annual and Final Report Forms.
4. Advise the Committee in writing as soon as practicable if the research project is discontinued.
5. Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research project, please email your request to the Research Ethics Officer at humanethics@usc.edu.au, detailing the nature of the change and your reasons for the request.
6. Submit a written request for an extension of ethics approval using the proforma 'Annual Report on Approval Research Project Involving Humans' (see section 9) or otherwise apply via email. The request for an extension does not alter the need to provide annual reports on the dates referred to in condition (3) above.

Please note that compliance with these conditions of approval is a requirement of the University's *Human Research Ethics – Governing Policy* and the *National Statement on Ethical Conduct in Human Research*.



A.2 RPIS

The lived experience of Complex Regional Pain Syndrome (CRPS).

Ethics approval number: (S/13/577)

Purpose

You are invited to take part in this project to allow us to examine the impact that CRPS has had on your life. The researchers will investigate what it's like to live with CRPS, what the impact your condition has on your life and that of your family and your health goals. Using information from people with CRPS, the research will identify strengths and weaknesses in current practice and will identify areas for improvement and reform.

Contacts

The research team consists of Chief Investigator Colleen Johnston (PhD candidate), Professor Marion Gray (Professor, Discipline and Program Leader, Occupational Therapy), Dr Florin Oprescu (Senior Lecturer, Health Promotion), and Professor Marianne Wallis (Professor of Nursing). Please direct questions to:

Colleen Johnston

Email:

Colleen.Johnston@research.usc.edu.au

Phone: 0405 820 012

Dr Florin Oprescu

Email:

foprescu@usc.edu.au

Phone: 5459 4639

Participant experience

You have been invited to take part in this project because you have been diagnosed with Complex Regional Pain Syndrome. If you agree to take part in this study, you will be asked to complete an interview with Colleen Johnston either face to face or via Skype which will take up to approximately 40 minutes of your time. The interview can take longer if you wish. The interview will be audio recorded with your permission and will ask about your experiences related to CRPS. You will be sent a copy of the transcript of the interview for your verification. The recording will be destroyed after transcription.

Risks and benefits

Psychological problems may be experienced by people telling their story. For instance, people may become upset during the interview or remain despondent



following its completion. While you will not receive any direct benefits for participating, your information will help us improve our knowledge of what it is like to live with CRPS. This information will help inform the health professionals involved in treating the condition which may lead to an improvement of services available.

Participation and consent

Participation in the interview is voluntary, and you may discontinue at any time without penalty. You may stop and restart your interview at your convenience. You may have a support person available or with you during the interview. If you are aged 14 and under, a parent or guardian must be present for the interview with you. You may use a pseudonym of your choice which will be non-identifiable by anyone apart from Colleen.

Written consent in person or via email will be obtained prior to commencing an interview. Consent is for the use of your interview data in this project. If you are aged 15 and under, your parent/guardian must also give their consent to you participating in the interview.

If you decide to withdraw from the research project, your data will be included in the final results, or will be destroyed at your request. You may withdraw consent at any time during the interview or upon reading the transcript.

Confidentiality and results

Your responses to this interview will be completely anonymous, and no one apart from Colleen Johnston will know who has participated. A summary of findings will be sent to you and made available on the Chronic Pain Australia and Australian RSD Support Group websites after analysis of the data. Non-identifiable results may be presented at external or internal conferences or meetings, or by publication.

Complaints / Concerns

If you have any complaints about the way this research project is being conducted you can raise them with the Chief Investigator. If you prefer an independent person, contact the Chairperson of the Human Research Ethics Committee at the University: (c/- the Research Ethics Officer, Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5459 4574; email humanethics@usc.edu.au).

The researchers and the University of the Sunshine Coast thank you for consideration of this study.

A.3 CONSENT FORM

Each participant was asked to provide written informed consent. The study was explained, and they were provided with a Participant Information and Consent Form. They were given time to decide whether they wished to participate in the interviews or not and each was assured their privacy would be maintained. While some participants preferred to use their own name, I am the only person who knows which participants have done this. Participants were told that I would not reveal who they are, but they may disclose this information if they wish to.



CONSENT TO PARTICIPATE IN RESEARCH

The lived experience of Complex Regional Pain Syndrome (CRPS)

(Ethics approval number S/13/577)

- I have read, understood and kept a copy of the Research Project Information Sheet for the above research project.
- I realise that this research project will be carried out as described in the Research Project Information Sheet.
- Any questions I have about this research project and my participation in it have been answered to my satisfaction.
- I agree to participate in the research project: *The lived experience of Complex Regional Pain Syndrome (CRPS)*.

Please sign and date this form to give your consent

Participant

Date

Parent/guardian for those aged 15 and under

Date

Skype Address of participant (if necessary)

In order to schedule the interview at a time convenient to you, please circle your preferred days and times.

Monday Tuesday Wednesday Thursday Friday Saturday Sunday

Morning Afternoon Night

Please email this completed consent to Colleen Johnston who will contact you regarding your interview Colleen.Johnston@research.usc.edu.au

APPENDIX B. Ethics documents for health practitioner interviews

B.1 HREC APPROVAL LETTER



1 August 2017

A/Prof Andrew Crowden
Chair, Human Research Ethics Committee
Tel: +61 7 5459 4574
Email: humanethics@usc.edu.au

F21825

Ms Colleen Johnston
Prof Marion Gray
Dr Florin Oprescu
Prof Marianne Wallis
University of the Sunshine Coast

Dear Colleen, Marion, Florin and Marianne

Expedited ethics approval for amended research project: The lived experience of Complex Regional Pain Syndrome (CRPS) (S/13/577)

This letter is to confirm that on 31 July 2017, as the Chairperson of the Human Research Ethics Committee of the University of the Sunshine Coast I granted expedited ethics approval for an amendment to the above project.

The amendment refers to the addition of health professionals as interview participants either as individuals or in groups; and the use and analysis of freely available online data posted in open forums such as web pages, blogs, YouTube, and Facebook from sources outside Australia.

The conditions for ethics approval for this project as outlined in our original letter of approval continue to apply.

If you have any queries in relation to this ethics approval or if you require further information please contact a Research Ethics Officer by email at humanethics@usc.edu.au or by telephone on +61 7 5459 4574 or 5430 2823.

Yours sincerely

A/Prof Andrew Crowden
Chair, Human Research Ethics Committee

The lived experience of Complex Regional Pain Syndrome (CRPS).

Ethics approval number: (S/13/577)

Purpose

You are invited to take part in this project to allow us to examine the impact that CRPS has on the lives of people diagnosed with CRPS. Using information from people with CRPS and health practitioners, the research will identify strengths and weaknesses in current practice and will identify areas for improvement and reform.

Contacts

The research team consists of Chief Investigator Colleen Johnston (PhD candidate), Professor Marion Gray (Associate Dean of Research), Dr Florin Oprescu (Senior Lecturer, Health Promotion), and Professor Marianne Wallis (Associate Dean of Health). Please direct questions to:

Colleen Johnston

Email:

Colleen.Johnston@research.usc.edu.au

Phone: 0405 820 012

Dr Florin Oprescu

Email:

foprescu@usc.edu.au

Phone: 5459 463

Participant experience

You have been invited to take part in this project because you are a health professional who interacts with people who have been diagnosed with Complex Regional Pain Syndrome. If you agree to take part in this study, you will be asked to complete an interview with Colleen Johnston either face to face or via Skype which will take up to approximately 40 minutes of your time. The interview can take longer if you wish. The interview will be audio recorded with your permission and will ask about your experiences related to caring for patients with CRPS. You will be sent a copy of the transcript of the interview for your verification if you wish. The recording will be destroyed after transcription.

Risks and benefits

Psychological problems may be experienced by people telling their story. For instance, people may become upset during the interview or remain



despondent following its completion. While you will not receive any direct benefits for participating, your information will help us improve our knowledge of what it is like to live with CRPS. This information will help inform the people living with CRPS and health professionals involved in treating the condition which may lead to an improvement of services available.

Participation and consent

Participation in the interview is voluntary, and you may discontinue at any time without penalty. You may stop and restart your interview at your convenience. You may be interviewed on your own or with other health professionals in a focus group if you wish. You may use a pseudonym of your choice which will be non-identifiable by anyone apart from Colleen.

Written consent in person or via email will be obtained prior to commencing an interview. Consent is for the use of your interview data in this project.

If you decide to withdraw from the research project, your data will be included in the final results, or will be destroyed at your request. You may withdraw consent at any time during the interview or upon reading the transcript.

Confidentiality and results

Your responses to this interview will be completely anonymous, and no one apart from Colleen Johnston will know who has participated. A summary of findings will be sent to you and made available on websites such as Chronic Pain Australia and Australian RSD Support Group after analysis of the data. Non-identifiable results may be presented at external or internal conferences or meetings, or by publication.

Complaints / Concerns

If you have any complaints about the way this research project is being conducted you can raise them with the Chief Investigator. If you prefer an independent person, contact the Chairperson of the Human Research Ethics Committee at the University: (c/- the Research Ethics Officer, Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5459 4574; email humanethics@usc.edu.au).

The researchers and the University of the Sunshine Coast thank you for consideration of this study.



CONSENT TO PARTICIPATE IN RESEARCH (HEALTH PRACTITIONERS)

The lived experience of Complex Regional Pain Syndrome (CRPS)

(Ethics approval number S/13/577)

- I have read, understood and kept a copy of the Research Project Information Sheet for Health Practitioners for the above research project.
- I realise that this research project will be carried out as described in the Research Project Information Sheet for Health Practitioners.
- Any questions I have about this research project and my participation in it have been answered to my satisfaction.

I agree to participate in the research project: *The lived experience of Complex Regional Pain Syndrome (CRPS)*.

Please sign and date this form to give your consent

Participant

Date

Skype Address of participant (if necessary)

In order to schedule the interview at a time convenient to you, please circle your preferred days and times.

Monday Tuesday Wednesday Thursday Friday Saturday Sunday

Morning Afternoon Night

Please email this completed consent to Colleen Johnston who will contact you regarding your interview Colleen.Johnston@research.usc.edu.au

APPENDIX C. Demographic details of the patient participants

The following vignettes have been written to provide a systematic and rich description of each participant's details and to extend the information provided in Table 2. Details include: age, country of residence at the time of the interview and time living with CRPS (in brackets), inciting injury, living circumstances (including socio-economic circumstances) and occupation. Additional data was included for context as deemed appropriate. The vignettes are arranged in ascending age order (from youngest participant to oldest participant). As information about me was included in the Introduction chapter, I have not included a vignette about myself.

Hannah

Hannah (22, Wales, 8 years) was 14 when she tore the tissue between her thumb and index finger in her dominant hand at school but was not diagnosed for about two years. She taught herself to write with her non-dominant hand so that she could complete her schooling. She initially had no treatment and then poor treatment and described her CRPS as deteriorating in her right and spreading into her left hand. At the time of her injury, Hannah lived with her parents and brother. Her brother had autism and an air drum tic. The vibrations set off pain in Hannah's arm and she tried not to be in the same room as him when she was at home.

Hannah was living in the city with a friend while completing an undergraduate degree. Motivation to continue her studies to PhD level came from a university supervisor who disclosed a diagnosis of fibromyalgia and encouraged Hannah to continue her studies despite living with chronic pain. She was completing her own CRPS research as part of her degree and hoped to have a career in educational psychology.

Because she pushed through and adapted to living with CRPS at a young age, Hannah was not consciously aware of most of the strategies she used to cope with her physical limitations unless her hand was 'really bad'. Her anxiety and depression were getting worse which she attributed to stress from university combined with CRPS. She spoke about not being able to do the things that a typical 22-year-old would do such as working in retail while studying. She did not work, and Hannah's parents had helped with financial issues when required. She stated that prescriptions in Wales are free. Her pain was usually well controlled, but Hannah suffered from brain fog as a result of medication.

Hannah described herself as lucky in that although her condition had worsened over the past few years, she could still manage it and did not remember what it was like to not have CRPS. She stated she still had a decent quality of life despite having CRPS.

Jasmine

Jasmine (25, USA, 13 years) developed CRPS as a 13-year-old child following an avulsion fracture to her ankle. She was diagnosed one year after her injury and had been taken to three or four different facilities before getting the CRPS diagnosis. CRPS spread to her knee when she sustained a meniscal tear at the age of 20, and the resulting body perception disturbance led to Jasmine requiring a wheelchair when she was 24. Jasmine walked around at home by hobbling and leaning on walls.

Jasmine was an only child living with her parents at the time of her first injury and had lived in various places since then, including at boarding school. She was living with her fiancée in a suburban town in order to complete a master's degree when interviewed. Her research involved CRPS. Attending school (university) was described as exhausting both mentally and physically.

As a teenager she tried to ignore her pain so as to not stand out as different and she was often accused of attention seeking or trying to get out of work or exercise. She never bothered to research CRPS because it scared her. She didn't like how she felt when taking opiates so pretended that although she travelled several hours for treatment, CRPS was not a big part of her life. She started ketamine treatment as a 17-year-old and found the first two infusions effective, but the ones following did not work. She then tried many other treatments.

Jasmine did not work, and her mother paid all her medical bills and was funding an upcoming trip to Italy for Neridronate treatment. Jasmine was being treated by two pain specialists, one in her home town and one in her current town. A dorsal root ganglion implant was also scheduled for Jasmine following the trip to Italy.

Laura

Laura (29, Australia, 15 years) sustained a meniscal tear to her right knee when she was 14 and was initially told by physiotherapists and surgeons that she was a hysterical teenager and a hypochondriac and needed a psychiatric referral for saying her pain had never gone away. At this time, she lived close to the city with her parents and younger brother and her condition caused problems between Laura and her brother for many years. After another meniscal tear following several falls when she was 20, the surgeon diagnosed her with CRPS and sent her to a specialist physiotherapist and a pain specialist. The specialist physiotherapist told Laura that she should drop out of university because she would never finish her degree and she would never work in her field. Laura graduated in the top 10 of her class of 80. After developing

dystonia in her foot, Laura was sent to another pain specialist who commenced Botox which was extremely painful and then tried a spinal cord stimulator and Baclofen pump.

Laura was a university student at this time and was attempting to do her clinical placement on crutches. It was winter, and she couldn't wear long pants or proper shoes until after the implant. She was getting very depressed. Around this time, Laura spoke to her doctor about self-harm and all the knives and medication in the house were put out of her reach.

After graduating and getting a job, Laura was mobilising with crutches and developed swelling and pain in her left foot and a spinal stimulator was inserted into her left leg. She also developed gastroparesis and spent one month in hospital and had a nasogastric tube for about 6 months. She never went back to work and was coping with many more co-morbidities which may or may not be attributed to CRPS.

Laura was working in a hobby/business which gave her something to concentrate on and kept her occupied but as she was on a disability pension, her financial future caused her to worry. She was living with her parents and relied on them to drive her to appointments etc and was not sure how long that could last as they were ageing. The specialist Laura was seeing was over an hour's drive away, so taxis were not a viable option for the future.

She did not remember life without CRPS, saying it was just part of her life. She had a big toolbox to manage her condition which included people such as her parents, doctors, her physiotherapist and some friends from a CRPS support group, and also medication, mindfulness, pets, and visualisation therapy. She used a wheelchair outside the house and tried to manage with crutches and furniture at home. She made a point of going shopping with her parents every Saturday morning, so she was out of the house for a few hours. She had trouble pacing herself and easily overdid things when she was feeling well.

She had a CRPS blog internet site of her own but did not keep it up to date.

Alice

Alice (30, Australia, 5 years) was working overseas when she injured her knee aged 25 and had to return home to a regional town. Within the first two months, Alice couldn't walk, and a physiotherapist suggested she might have CRPS. She then saw multiple doctors who disbelieved her, and it spread to her entire leg before she was diagnosed with CRPS by a sports doctor nine months after the injury.

Alice had tried many medications and treatments including nerve blocks and spinal cord stimulation but said that nothing had worked. Within the first year CRPS had spread to both

legs and hips, then to her spine. Around the third year she had CRPS in both arms and hands and she was losing teeth due to it being in her mouth. She stated that it had recently spread to her lungs, stomach and digestive system when she was interviewed.

Alice lived at home with her parents and was on a disability pension. The family had been forced to move to a house that could accommodate her disability and wheelchair. There was a financial burden on her father for medical bills for Alice and her mother was chronically ill and unable to work.

Showers were painful for Alice, so she showered once or twice a week. She wore incontinence pads and tried to move every 20 to 30 minutes because pressure on her body caused pain. She was usually able to cook the family meals and tried to go on the train to the city to meet her small group of friends every fortnight. She was hoping to get a licence and hand controls for a car so that she could have some more independence. Another goal for Alice was to lose the 40 kilograms she had put on from medication and had lost about 16 kilograms when interviewed.

Alice tried to spread awareness during the CRPS awareness month of November. She had sold orange ribbons and t-shirts at markets and used every opportunity to speak to people about her condition.

Martin

Martin (32, England, 5 years) lived in a city in England and developed leg pain a week after being in a car accident. His initial diagnosis was whiplash and referred back pain. He saw the foot clinic at his local hospital and was eventually referred to a public orthopaedic specialist. An appointment was not available for six months and Martin's wife managed to get a private appointment with the same doctor with less waiting time. The orthopaedic doctor suspected CRPS.

Martin saw that doctor through the public system and a cycle of x-rays, MRIs and very little treatment commenced. A specialist CRPS program had been mentioned but the orthopaedic doctor and the GP did not know how to get Martin an appointment there. Martin's father-in-law rang them and a few months later Martin had an appointment at the specialist centre who confirmed the CRPS diagnosis and directed him to resources and accurate information.

Martin initially expected the inpatient course at the specialist centre would cure him. He then realised he was being trained in how to live with CRPS. He had been using a single crutch which was too small to help him walk for 18 months before attending the program and had developed a carpal tunnel in his left wrist. He then developed another carpal tunnel in his right

wrist and CRPS in his left wrist. He was looking at getting a wheelchair for those times he was unable to mobilise with crutches.

Martin was unable to continue in his job and it had taken six months to gain further employment with another company, but he was made redundant within six months. Nine months later he found another job which did not require anything physical. He found that the transition from being a physically active person to requiring aids in the house frustrating and had refused hand rails on the stairs because he did not want physical signs of his disability everywhere. He had rails in the bathroom and a perching stool in the kitchen. He had a custom-made pram so that he could push his 8-month-old baby in it.

Martin wanted to raise awareness for CRPS and was considering participating in a marathon.

Fred

Fred (41, Australia, 11 years) had CRPS for 11 years and lived in a capital city with his wife and 4 children. He suffered a crush injury and ligament damage to his arm at work but as he does not like them, he didn't see a doctor for six months when he became unable to drive. The surgeon neglected to tell him he had inserted two pins into his arm and also didn't tell the physiotherapists he worked with. This resulted in Fred using a TENS machine which caused further harm. CRPS was diagnosed two years after that but Fred was told that CRPS is just excessive pain. Fred did not know that the other symptoms he was experiencing were part of CRPS and he thought he was going crazy. When he mentioned that the pain was spreading into his hand and he was unable to make a fist, he was told that it was 'silly' by a pain specialist.

A pain clinic wanted to perform a spinal block, but Fred has a needle phobia and fainted at the first attempt. He was told that unless he had morphine injected into his spine he couldn't have mirror box treatment. Therefore, Fred had no treatment and the CRPS spread throughout his arm and to his stomach and neck causing vomiting and headaches. He told of extreme temperature changes in his body from being boiling hot to being so cold he shakes so violently that he has torn chest muscles.

Fred's problems with WorkCover have lasted 11 years and have affected the family finances. With four children to provide for, Fred's wife is his carer but she also worked four days a week outside the home. As Fred was often unable to leave the house he missed a lot of family events, including Christmas day at his mother's house.

Fred's work was also his hobby and he missed that more than anything else. He used to enjoy fishing but being unable to wind his own rod, he gave it up. Fred was spending his days

watching TV and playing computer games on his own which he never did before the injury. His friends had abandoned him completely once he could no longer drive due to a combination of brain fog and pain. He had to reduce his opiate dose due to being 'spaced out' and found he tired easily and had trouble maintaining conversations. Most medications had little or no effect on his pain levels and he described his pain level as 9.549012 on his current medication stating that it had reduced his pain.

Fred wanted to see a pain specialist again but said he need a break from fighting WorkCover to pay for it. He had held his arm in the one position for so long that his elbow no longer straightened, and his shoulder had little movement. After researching CRPS on the internet, Fred discovered that his odd symptoms of chronic fatigue, rashes and increased sweating were part of CRPS and he said it felt good to know that he wasn't alone in how he was feeling.

Fred decided to help other people in similar positions and was planning to make YouTube videos featuring people with CRPS (including someone who has gone into remission) so that others in his position could learn. He had already made a short video explaining CRPS in his own words so that non-medical people with brain fog would be able to understand it. This was a project he could do when he was feeling well.

Mel

Mel (41, Australia, 9 years) lived in a regional town. An incident at work caused torn cartilage and a Bankart Lesion in her shoulder and all her treatment had to be approved by WorkCover. After a physiotherapist suggested CRPS, Mel was referred to an orthopaedic surgeon and a pain clinic where the diagnosis was confirmed. This was four and a half years after the injury. She left the pain clinic after dry needling to her shoulder caused immense pain and saw another pain specialist who recommended ketamine infusions and a spinal cord stimulator.

WorkCover refused permission for these procedures, so Mel tried alternative therapies including kinesiology and acupuncture. At the court case, Mel was accused of being a drug addict and faking her condition despite the diagnosis being confirmed by two pain management specialists. This caused financial problems so bad that Mel was considering declaring bankruptcy at the time of her interview. She had been unable to work since her injury and had a dependant teenager at home.

Mel found it difficult to perform tasks with her non-dominant hand and had altered her routine to cope with her disability. She sold her manual car and bought an automatic with a

steering wheel knob. She shopped daily because she was unable to push a shopping trolley. She used frozen vegetables, ate a lot of mince and made meals in the slow cooker as much as possible. She used an electric toothbrush and had pump shampoo and conditioners which she could managed one handed. Mel could not wear a bra and none of her clothing had zips or buttons. She said her life was going really well until CRPS took away all her hopes and dreams.

Emma

Emma (45, Singapore, 1 year) had a master's degree and lived on her own. She had a spiral fracture to a finger in her dominant hand and her surgeon diagnosed CRPS within three or four weeks. Lyrica made her too 'spacey', so she stopped taking it and started meditating and being mindful. She was unable to bend her finger and attended a physiotherapist but her CRPS was easily aggravated. She bandaged her finger to help with stability and swelling.

Medical care in Singapore was described as expensive and as Emma is self-employed, she could not access sick leave. She had been battling her medical insurance company for almost 12 months and stated she was lucky that her surgeon had not charged her for everything. Her physiotherapy appointments were not covered by insurance.

Her surgeon and physiotherapist were familiar with CRPS, so Emma had expert care from the time of injury. Emma credits her surgeon who is a Buddhist for introducing her to meditation which along with mindfulness was the best support she has found.

Emma stated she had more trouble with her finger when she was in England on holidays due to the colder weather.

Sarah

Sarah (45, England, 16 months) developed CRPS post knee surgery and it took 13 months for her to be diagnosed. She saw a local doctor who referred her to an orthopaedic surgeon, a pain management specialist and a rheumatologist. The rheumatologist suspected CRPS and the diagnosis was confirmed by a CRPS specialist centre. She had been working in her own business but had to stop due to pain. As a consequence, Sarah and her husband moved to a fairly rural area in England so that they could buy a bungalow and no longer have a mortgage.

She was looking forward to an inpatient stay at a pain management program and as she was having difficulty accepting her diagnosis was going to see a psychologist and explore future work options with an OT while there. She was using a tens machine constantly and was going to discuss a spinal cord stimulator with a CRPS specialist she had been referred to. The

medication was causing her to have memory problems which she hoped would be solved with surgical options.

Sarah used a scooter to mobilise and had changed her car so that it included a hoist for the scooter. Although the government could have supplied the vehicle, it took so long that Sarah ended up paying for it herself. As she was not working she described it as a very expensive time. A social worker had recommended care so that Sarah's husband (her carer) could get a break. This was something they could not afford, and Sarah was worried because her husband had already hurt his back through looking after her.

Sarah wanted to raise awareness and wanted to be involved in Colour the World Orange Day in November. She gets frustrated with the amounts of money being raised for cancer and wanted to do some promotion that helped to make people aware of her condition.

Sharon

Sharon (46, Australia, 5 years) lived on the outskirts of a capital city with her 18-year-old son. After injuring her wrist Sharon was in plaster for ten weeks. She had been working in two jobs and had to give both of them up after hurting her wrist. She described feeling like acid had been poured down her cast and knew something was wrong, but no one believed her. CRPS was suspected by a hand specialist but the doctor at the public pain clinic she was referred to didn't believe her. She was bullied by the doctor who said she had arthritis and a psychological problem.

Lyrica was too expensive at the time, so Sharon took pain killers and did a pain program where she learnt art therapy, meditation, graded motor imagery and did hydrotherapy. After asking for a second opinion for two and a half years, Sharon finally saw another doctor who officially diagnosed her with CRPS. After nerve blocks did not work, Sharon started ketamine infusions which made a big difference to her pain levels. The combination of medication and a sedentary lifestyle caused Sharon to gain 40 of 50 kilograms which caused additional problems.

At the time of interview, Sharon had swelling and redness from her fingers to between her elbow and shoulder on the right side. Her right shoulder and right side of her face were also red and swollen. She required carers every day to help her wash and dress and they would come back at lunchtime to make lunch and dinner and assist her to the toilet. Getting assistance at her age was extremely difficult. After having a fall and having no use of either arm, Sharon was told she wasn't disabled enough for a disability pension until she said she had depression. That process took six months.

After developing bowel and bladder issues, and being unable to self-care, depression did become a problem and Sharon's elderly mother came to help at times. Sharon did not think it appropriate for her son to assist her with hygiene care. She felt she had lost all her independence once she couldn't get herself to the bathroom or change her underwear. The carers though, did not always turn up and Sharon couldn't go out on her birthday two years in a row because she was unable to get dressed. Some carers did not understand the magnitude of the pain if they touched certain parts of Sharon's arm which could cause her to be bedridden for months. She developed seizure like attacks because showering was sometimes so traumatic.

Hospital stays for ketamine infusions were also traumatic and doctors and nurses disbelieving Sharon's pain were common. She said that being a patient in the surgical wards was better because the nurses were too busy to bully her about the opiate prescriptions written by her pain specialist.

Sharon required community services to drive her to the hospital for appointments. Her mother accompanied her when possible as Sharon was not confident being out on her own. One time, she was unable to walk from the drop off point to the clinic on her own and had gone home without getting to her appointment on the next floor. The community car would not drive Sharon's mother home as she was not a client and although she had early stage dementia, she was forced to get a bus home after accompanying Sharon to hospital for a ketamine infusion.

Dianne

Dianne (50, England, 4.5 years) injured her shoulder during a Pilates class. During the first 12 months she saw a GP, physiotherapist, a neurologist, a vascular surgeon, an orthopaedic surgeon and had stopped using her arm due to excruciating pain. Dianne went to another physiotherapist who mentioned CRPS and told her to carry on doing things and just forget about it and the CRPS will melt away. Dianne's GP refused to refer to her to a specialist CRPS centre she had heard about incorrectly reasoning that it was too expensive.

Another GP referred Dianne to a CRPS doctor and she waited a long time for the appointment. She was told by this doctor that because she'd had it for three years, there was nothing that could be done, and that Dianne would just have to live with the pain. During this time, Dianne lost her job, could no longer drive, and as a health care professional, was frustrated knowing that her condition was very treatable if she had been diagnosed and treated earlier.

Dianne got a referral to the specialist centre she had originally asked about. She had two admissions to this centre where she received medication, education and therapy. She was

taught to meditate and taught how to start re-using her right hand again. The specialist centre helped Dianne to adjust her routines. She started wearing a bra again for increasing lengths of time when leaving the house and told how she was wearing tops two sizes too big so that the material touching her inner arm, elbow, wrist and palm did not hurt. Before that, she had been wearing nothing on her top half at home because instinctively she wanted to avoid pain. She was slowly overcoming disassociation of her affected arm.

Dianne had a masters level education and had earned more than her husband prior to leaving work. She felt guilty that she was not earning an income because she could no longer help her young adult children financially. She also could not help her elderly parents. One of her goals was to be able to wear a variety of clothing and feel like herself again. Her other goals were to gain a part time or casual job where she could work from home and to be able to participate in a yoga class.

Karen

Karen (55, Australia, 7 years) lived with her husband and teenaged daughter on the outskirts of a capital city. She suffered a spiral fracture to her foot on public transport and it took three years for her to be diagnosed with CRPS. She saw a physiotherapist and had two lots of surgery during this time. The pain specialist who diagnosed her forgot to write to the insurance company for permission for ketamine treatment three months in a row, so Karen organised to see another pain specialist who apart from referring her to a psychologist, did nothing besides writing prescriptions for medication. In this time, Karen went from limping to using a walking stick to using crutches full time and had a physical deformity to her foot.

Karen sought advice from an online support group and was recommended another pain specialist. There was a long waiting period to see the new specialist and he was on the other side of the city. The insurance was going to pay for her treatment, but the claim took 12 months and was extremely stressful both mentally and physically for a small financial gain.

She worked full time for years with CRPS and gave up on the advice of her GP as she was getting too tired to drive home safely after work. Karen used to be very social and did not go out much anymore due to the difficulty mobilising, the pain and the exhaustion afterwards.

There was a big impact on Karen's family following her injury and her husband had to do most of the housework and care of their teenage children which Karen felt guilty about. She was looking forward to getting a power assisted wheelchair so that she would have some more independence.

Jackie

Jackie (55, England, 4 months) lived with her mother in a large city. She broke her wrist and was in continuous pain for the next three months getting her wrist replastered multiple times. She found herself a private physiotherapist who could see her the day the hospital had told her she would be given an appointment within the next few weeks. This physiotherapist suggested she had CRPS. This was confirmed by a pain management specialist who did not explain the condition or its treatment to Jackie. Jackie did not like how the Gabapentin made her feel. She said she was usually an organised person but had brain fog and worried she was rambling.

Jackie continued to see the private physiotherapist after she was given public appointments because she had been told she required intensive physiotherapy and she did not think weekly appointments were enough. She had physiotherapy four times a week and then commenced alternate therapies including acupuncture, osteopathy and electric differential treatment. She underwent a three-hour myofascial treatment which she described as very, very painful and the practitioner told her that she was feeling all her emotions. Jackie also put frankincense and myrrh on her arm and also a wintergreen concoction on her hand. She developed a rash which that practitioner explained as the gabapentin coming out of her body. The pain in her hand from seven and a half hours of chakra cleansing was explained as toxins leaving her body and when she had meditation with crystal gong healing that practitioner said she was carrying the emotional burdens of other people.

Paul

Paul (58, England, 8 years) had broken his right ankle and developed CRPS eight years before his interview. He was diagnosed after discussing symptoms with another person and asking his GP for a referral to a specialist centre.

Paul a former tradesman had divorced in the 12 months before we spoke and as he was about to move house, he described his situation as stressful. He thought these were contributing factors to CRPS spreading down his right-hand side and right arm. He used a reminder on his phone so as to not forget to take his medication.

After spending two and a half years at home, Paul got a mobility scooter which gave him some independence. At home he used two crutches and he had a 'motorbility' car which has been adapted so that he can drive himself.

Living in a small rural village was a benefit to Paul because the villagers all knew him and how he was injured so he had a lot of acceptance in his community. Being diagnosed and having a name for his condition also helped acceptance. Paul inserted a lot of CRPS information into his care plan book which the carers who assisted him each morning read before providing care. Getting a state-based benefit and an early work-based pension was difficult as he was not believed by the people in authority.

One thing Paul did find difficult was that despite having more than one inpatient stay in a pain clinic he had to be referred again to go back. Paul became involved in amateur radio which gave him a hobby where he could talk to people throughout the world.

Rosemary

Rosemary (64, Australia, 8 years) lived in a rural area with her husband who was her carer. Her CRPS started after developing pain in her foot which was eventually diagnosed as a neuroma. She saw many health professionals both private and public during the next five years. Rosemary had three surgeries on her foot performed by three different surgeons and her pain levels were not acknowledged until her last surgery. She saw two pain management specialists and eventually gave up on doctors after feeling she was not being taken seriously. It was taking her three hours to get to the city and at least two hours to travel to larger towns for treatment and the travel was aggravating her pain.

Five years after the pain started, Rosemary saw another pain management specialist who diagnosed CRPS and suggested spinal cord stimulation. Four months later she was still waiting to be booked in and decided to give up on the public system. After asking for suggestions on an internet forum, Rosemary made an appointment with a new specialist in the city. Six years after the initial surgery, Rosemary received a spinal cord stimulator trial and an implant four months after that.

She changed to a new private pain clinic in a regional town that was two hours away, saving her one hour travel each way. They started her on ketamine infusions and she saw a physiotherapist who taught her how to pace herself by limiting the time weight bearing to avoid flaring her foot.

Rosemary had contemplated suicide in that first five years and credits the local psychologist she was seeing for helping her to find a way to live with her pain. She said she was fortunate that she had private health insurance and no mortgage to cause major financial concerns. After giving up work due to pain, Rosemary said she found a new identity as an artist and converted a carport into a studio in her backyard. She was able to work on her art and unless

the pain was really severe to direct all her attention to creating the artwork, describing it as an almost meditative state.

Rosemary had a number of mobility aids. At home she used crutches and a knee walker which she sourced from America. When leaving the house, she preferred a portable scooter which she described as much easier to manage in public than her wheelchair. Rosemary didn't go out very often which she felt guilty about because her husband and her had planned to travel when they retired. They liked to take drives and do sketches together but every outing had the potential to cause pain.

Rosemary directed me to her CRPS website during her interview. She made the site after experiencing difficulty getting home help and wanted people to know that her condition and physical limitations can change on a daily basis.

Carolyn

Carolyn (65, England, 18 years) lived with her husband in a rural village and her CRPS started with a pain in her elbow. It took three and a half years for her to be diagnosed with CRPS. A second injury following this caused CRPS in her leg. She had recently retired to spend time with her grandson.

Carolyn said her biggest challenge was walking, and she had an electric scooter but said that the hardest thing to overcome was losing her independence. She had been driving with a steering wheel knob but had 'wobbly' sessions, so it was no longer safe. She also required someone to cut up her food and needed help to get dressed.

Her family had developed strategies over the years to make life easier. An example being that they walked on her affected side in crowds so that no one could bump her. She felt that if she sat around at home all day she would be bored. The pain management clinic she attended had taught her techniques so that she could interact with her grandchildren when they were born, and she had learned to knit after she retired. Carolyn said she might turn into a cabbage if she didn't keep doing things. She did not want to walk around with a label saying she is disabled she just wanted to try to fight it.