



Patients Describe their Lived Experiences of Battling to Live with Complex Regional Pain Syndrome

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Abstract: Complex regional pain syndrome (CRPS) has never comprehensively been examined from a lived experience perspective. Patients generally have a poorer quality of life than people with other chronic pain conditions. This study aimed to understand the essence of living with CRPS. Data were collected from 17 patients via in-depth interviews. Hermeneutic discussions with four health professionals generated deeper insights. Internet blogs and a book containing patient stories were included for theme verification and triangulation. CRPS is seen as a war-like experience and five themes were identified within the battle: "dealing with the unknown enemy", "building an armoury against a moving target", "battles within the war", "developing battle plans with allies" and "warrior or prisoner of war". Patients live with a chronic pain condition and experience problems unique to CRPS such as fear of pain extending to other parts of their body. Use of the model generated by this research may assist patient/clinician interactions and guide therapeutic discussions. Support for people living with CRPS does not always exist, and some healthcare professionals require additional education about the condition. Better health outcomes are experienced by patients when their personal situation and experiences are heard and understood by health care professionals.

Perspective: This article presents the lived experience of CRPS. This information and the model generated can help clinicians to better understand their patients and deliver appropriate patient-centered care.

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Key words: Complex regional pain syndrome, CRPS, Phenomenology, Qualitative research, Lived experience, Chronic pain.

Introduction

Complex regional pain syndrome (CRPS) is a condition which is difficult to diagnose, difficult to treat, and unlike other chronic pain conditions, it can

spread to encompass other parts of the body.^{8, 32, 48} It is reputed to be the most painful condition known to man as measured by the McGill Pain scale, rating higher than amputation of a digit, childbirth and cancer pain.^{8, 32, 59} Previously known as reflex sympathetic dystrophy (RSD), causalgia and shoulder-hand syndrome, CRPS is largely unknown in the general public and many health professionals will not encounter or recognise it in clinical practice.^{8, 38}

CRPS causes are unknown; it usually develops after injury though spontaneous development can occur.^{8, 23} Between 4 and 7% of patients who have undergone limb surgery, are likely to develop CRPS, although fractured limbs, sprains, bruises, intravenous cannulation, injections and stroke are also known causes.^{6, 8, 61} It is most common in upper extremities, with approximately

Received November 4, 2020; Revised February 27, 2021; Accepted March 16, 2021.

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

There are no conflicts of interest to declare.

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<https://doi.org/10.1016/j.jpain.2021.03.151>

60% in the arm and 40% in the leg.^{32, 44} Affecting more women than men, the average age of incidence is anywhere between 36 to 70 years of age, although children as young as 2 are known to have been diagnosed.^{8, 32, 38}

While there are a variety of presentations between patients who report symptoms such as hyperalgesia, oedema, temperature and colour changes, allodynia, and abnormal sweating, the common symptom is pain disproportionate to the precipitating event.^{8, 47} Research indicates that while most cases show improvement within the first 6 months, few cases resolve completely within 12 months of onset,³ and a small subset of approximately 15% of patients progress to chronic CRPS, with unrelenting pain and physical impairment two years after symptom onset.^{9, 23}

The goals of CRPS care are mainly pain reduction and restoration or improvement of function and treatment is considered to be palliative rather than curative.^{5, 23, 31, 65} Defining recovery in CRPS is difficult because people may be symptomatic yet no longer meet the diagnostic criteria.^{23, 42} Prompt diagnosis and early intervention usually result in better psychological outcomes for the patient and less physical problems due to neglect or disuse of the affected limb.^{3, 8, 23}

However, some people experience delayed diagnosis. Despite initial florid symptoms, patients are often misdiagnosed and disbelieved about the extent of their pain by health professionals.²³ It can take patients up to 30 months to be diagnosed and referred to a specialist pain centre for treatment, and during the time between the onset of symptoms and diagnosis, as with other undiagnosed chronic pain conditions, the pain is known to cause vulnerability and suffering in the patient.^{1, 19}

Living with CRPS can be debilitating and people with CRPS generally have a poorer quality of life and may have a higher risk of suicide than people with other chronic pain conditions.^{32, 39, 65} CRPS patients deal with all the usual problems experienced by patients with chronic pain but have added unique complications.³⁴ These include vasomotor symptoms, trophic signs, tremor, restricted range of movement, and poor skin healing.⁶⁰ Allodynia, hyperalgesia and central nervous system changes are also seen, and like fibromyalgia, results in more disability and a higher service use than people living with other pain conditions.⁶⁰

Research to date has largely been quantitative, following the medical model of disease, concentrating on understanding pathophysiology, diagnosis and treatment, and determining measurable indicators for CRPS.^{53, 54} To date, little qualitative research has been performed to better understand the lived experience of CRPS. Thus, the aim of this was to better understand the phenomenon of chronic pain from the lived experience perspective of people living with CRPS.

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The Study

Study Design - Heuristic Hermeneutic Phenomenology

Phenomenology has been described as an attempt “to explicate the meanings as we live them in our everyday existence.”⁶² Hermeneutic phenomenology is the study of phenomena using lived experience as data to discover the essence of the phenomenon.^{40, 62, 63} This study used elements of heuristics in a hermeneutic phenomenological approach as detailed by Johnston et al.³⁵ Heuristics enables an insider perspective without that perspective dominating the research.⁴⁶ This method permitted data from the first author's experience of CRPS to be used to explicate their assumptions and pre-understandings, helping with the descriptive clarity and study rigour.⁴⁰ The insider perspective also provided additional data for inclusion in the analysis. This research was situated within the work of van Manen⁶² who describes the process of transforming descriptions of lived experience into a textual representation.

Ethics and Recruitment

Ethical approval was granted by the University of the Sunshine Coast Human Research Ethics Committee (Approval number S/13/577).

A purposive sampling technique was used. Initially, we recruited people with CRPS from online forums in Australia. To ensure a wide range of perspectives that represented the lived experience of CRPS worldwide, a convenience sample of participants in other countries were then recruited from online forums, and open and closed Facebook groups. For triangulation and comparison purposes a convenience sample of health professional (HP) participants was recruited via an International Association for the Study of Pain (IASP) Special Interest Group for CRPS Conference.

Inclusion Criteria

To be included in the study participants had to be able to speak English and have been formally diagnosed with CRPS. Within this group there were no exclusion criteria, all who volunteered and were available within the interviewing period were interviewed. Participants described how they were diagnosed and who provided the diagnosis. As some participants had not been told if they had Type 1 or Type 2, this information was not collected. Due to the 18-year range of symptoms, participants were diagnosed using different criteria. Potential participants who could not provide information on how they were diagnosed were not included as participants. Written proof of diagnosis was not required, which is consistent with previous and current CRPS research.^{41, 48, 60}

Data Collection from Patient Participants

Five pilot interviews were conducted to help to refine the interview questions and prepare the interview

guide. The first author conducted semi-structured, conversational style interviews face to face, via skype or telephone at the convenience of the participant. Prior to each interview, each participant signed a consent form and chose a pseudonym. Each participant was made aware that the first author also has CRPS and was also interviewed for the study. In line with accepted phenomenological principles and recommendations⁵⁵ each interview commenced with the following prompt: "please tell me your story about living with CRPS". (See supplementary material for the interview guide).

Audiotaped interviews were transcribed for analysis. In total, 19 interviews were conducted and 17 were analysed between 2016 and 2017. Three of the pilot interviews that met the inclusion criteria were included in the analysis.

Data from the Insider Perspective

After pilot interviews and the interview guide were finalised, the first author (a registered nurse, who had been diagnosed with CRPS four years prior) was interviewed (by another researcher who has experience as a medical practitioner and has clinical experience working with people diagnosed with CRPS) as a participant, following the guidelines suggested by Johnston et al.³⁵ Readers are directed to this publication for further information about use of data from the lived experience of the researcher within phenomenology.

Data Collection from Health Professionals

Although most health professionals (HPs) may not have personal experience living with CRPS, they are often an important part of the life context of patients. Their interactions with patients can influence the course of the health/illness trajectory and their perceptions can influence policy and procedures regarding patient management. To gain greater understanding and generate deeper insights, the emerging themes from the patient interviews were discussed with four HPs during semi-structured interviews. Van Manen⁶² believes that such collaborative conversations or hermeneutic discussions on themes and thematic descriptions of phenomenon allow researchers to transcend the limits of their present vision. Additionally, he suggests that a professional practitioner can be consulted for their interpretive insights to assist in the elucidation of the accounts of lived experience that lie within the range of their professional experience.

The CRPS research community is quite small, and these participants are considered to be leading world experts in CRPS. As such, they are easily identifiable. Therefore, demographic information is presented so that participant (and non-participant) anonymity could be maintained.

Additional Data

In accordance with the methodology utilised, additional data sources were consulted to generate deeper insights and to determine the essential themes and

distinguish them from the incidental themes.⁶² The first 5 internet sites discovered when searching 'blogs about living with CRPS' on Google were used. In addition, ten patient stories contained in a book⁵⁰ provided another data source and facilitated the validation of themes. Rodham⁵⁰ was the only book about living with CRPS, which included patient stories found when searching Google up to March 2016. The additional data sources 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)
- "Learning to Cope With CRPS/RSD: Putting Life First and Pain Second". Karen Rodham (2015).

Refer to Fig 1 for flow diagram of the recruitment and analysis timeline.

Analysis

Primary and secondary data sources were analysed using the steps recommended by Van Manen, which encourages a deep level of contemplation of the experience so that meaning and understanding can be reached.⁶² van Manen identified 4 aspects to the existential experience, which include: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality, which "belong to the fundamental structure of the life-world".⁶² He offers these four existentials as guides to questioning, reflection and writing in the hermeneutic phenomenological research process. Data analysis was completed manually as is usual in a phenomenological study. Interview transcripts were read multiple times by the first author and coding terms were identified and reflected upon, guided by the existentials. Third-party verification of codes was undertaken by all authors. Transcripts or sections of transcripts were coded separately by each author and the consensus discussions which followed resulted in the creation and definition of common coding terms. These terms were clustered to find commonality in the participants' stories. The additional data sources were then analysed.

Rigour

The thematic analysis approach of holistic, selective and detailed reading⁶² was applied to the additional data as with the interview transcripts. The common coding terms previously identified were appropriate to use when analysing data from the patient stories in the book and internet blogs. Thematic statements were then isolated, determining the essential themes and



Figure 1. Recruitment and analysis flowchart.

distinguishing them from incidental themes.⁶² The process of examining the additional data also assisted with triangulation and helped to ensure phenomenological trustworthiness and rigour.^{29, 40, 62} Rather than using a pseudonym, the first authors first name was used throughout the study so that her data remained transparent to limit potential bias in the analysis. This aided coresearchers to follow the decision trail and ensure rigour.⁴⁰

Findings

Seventeen people participated in the initial interview process. Amongst the participants, three were men and fourteen were women. Participants' demographics resembled the demographics of the CRPS population. Ages of participants in this research ranged from 22 to 65 years (mean = 44 years). There were 8 Australians, 6

Table 1. Patient participant demographics

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 y	3 y	Diploma	Foot	Husband, daughter (17)
Laura	29	15 y	9 y	Degree	Leg	Parents
Rosemary	64	8 y	5 y	Diploma	Foot	Husband
Colleen	48	4.5 y	3 wk	PhD	Hand	3 sons (17, 15, 13)
Sharon	46	5 y	4 mo (3 y formal)	Year 12	Hand	1 son (18)
Fred	41	11 y	2½ y	Year 8	Arm	Wife and 4 children (9–19)
Martin	32	5 y	5 mo (18 mo formal)	A levels Apprenticeship	Foot	Wife, baby (8 mo)
Emma	45	1 y	3–4 wk	Masters	Hand	Self
Jackie	55	4 mo	3 mo	High School	Hand	Mother
Hannah	22	8 y	2 y	Degree	Hand	Friend
Alice	30	5 y	9 mo	TAFE cert 3	Leg	Parents
Dianne	50	4.5 y	3 y	Masters	Shoulder	Husband
Jasmine	25	13 y	12 mo	Masters	Ankle	Fiancé
Sarah	45	16 mo	13 mo	Post graduate certificate	Knee	Husband
Mel	41	9 y	4.5 y	TAFE cert 3	Shoulder	1 son (18)
Carolyn	65	18 y	Nearly 3 y	A levels	Arm then leg	Husband
Paul	58	8 y	2.5 y	O levels A levels trade certificate	Leg	Self

participants from England and one each from Wales, USA, and Singapore. Participants had experienced symptoms from 4 months to 18 years (mean = 7 years). Eight participants had CRPS in a lower limb, 8 in an upper limb and 1 person had it in both upper and lower limbs. As there is no relevance for the management of CRPS according to evidence of nerve injury (Type 2 CRPS) or not (Type 1), this information was not obtained.^{23, 42} Further demographic information is available in Table 1.

Participants time to formal diagnosis ranged from 3 weeks to 9 years (mean = 2.65 years) as shown in Fig 2.

Four interviews were conducted with health professionals. They resided and worked in three different countries and had worked with CRPS patients for between 20 and 27 years (a mean of 23.5 years). There was an even gender mix and they had all worked or were currently working in clinical areas and they all had extensive research experience. Refer to Table 2 for further information.

The Battle

Patient interviews and additional sources resoundingly described life with CRPS as a constant battle, fought by individuals who have had minimal preparation, ad hoc weapons, ad hoc or even absent back up with a terrain that keeps shifting. Hermeneutic reflection of the data revealed that the battle concept was supported in the blogs, book, and HP interviews. Three people quoted in the book, four of the bloggers and 8 interview participants stated they were “*fighting*”, in a “*battle*”, or were “*battling*” their condition. In other words, ‘living with CRPS is a battle and CRPS is the enemy’. Additionally, many internet sites described members as “*warriors*”. (e.g., see <https://rsds.org/true-definition-crps-warrior/>). Products including t-shirts, keyrings and cups are available to purchase from online stores (such as <https://www.amazon.com/CRPS-Awareness-Shirt-Warrior-Fighting/dp/B07FH8C823>) using the term CRPS Warrior. Patients, and to an extent HPs and

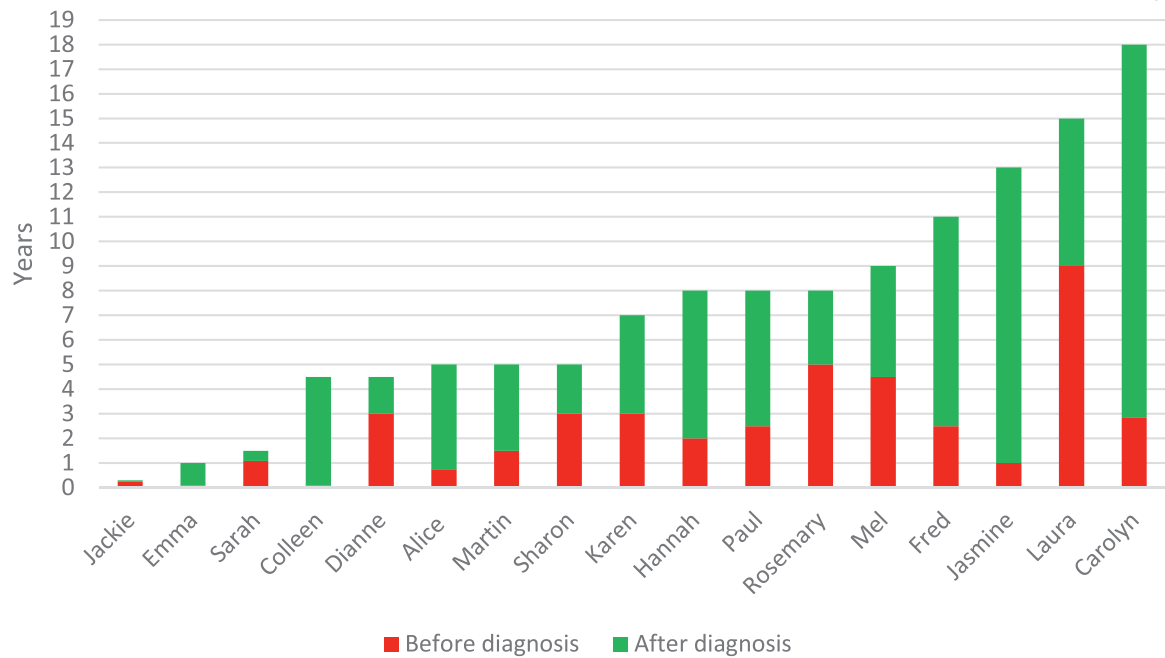


Figure 2. Time from initial symptoms to formal diagnosis.

researchers, are the ‘warriors’ or ‘soldiers’ fighting it. (It is acknowledged that although engaged in a battle, the lifeworld of CRPS is vastly different for patients and HPs who live and experience separate aspects of the disease). Five distinct, yet overlapping themes were identified within the battle and keeping with the metaphor, they were named as follows:

- Dealing with the unknown enemy
- Building an armoury against a moving target
- Battles within the war
- Developing battle plans with allies
- Warrior or prisoner of war

The themes and their sub-themes are detailed in the next sections together with relevant quotes from the interviews, book and blogs. As the primary data source, the interview participant quotes are cited most often.

Theme 1. Dealing with An Unknown Enemy

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

The Unknown Aetiology

CRPS aetiology is still largely unknown. This makes the condition difficult to live with. HP1 felt that the ‘hypersensitivity in CRPS is greater than you see with many other pain conditions, which I think interferes with functioning for many patients’. HP1 felt that although there is overlap with other pain conditions, as a researcher, the differences with other conditions “makes it more interesting. There is more that I think is unknown in CRPS than many other conditions”.

Table 2. 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
First heard of CRPS	Journal club as a clinician	University – initial degree	At work through clinical supervisor	University – initial degree

CRPS is a Rare and Largely Unknown Condition

Finding a diagnosis was a long process for most participants who felt there was *"something wrong"* but were often not believed. After being called *"a hypochondriac, hysterical teenager"*, Laura was told, *"it's all in your head"*. Rosemary described going on a *"quest"* for a diagnosis, consulting many HPs and receiving multiple incorrect diagnoses which resulted in inappropriate treatment and large financial outlay.

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 discussed physical therapy causing increased pain, Dianne spoke of being in tears due to a physiotherapist who was *"very unsupportive, almost as though he really didn't believe the level of pain that I was in"* and medication prescriptions which were often ineffective. Many expressed the wish to have *"a more common condition, like cancer"* and felt they were not understood and not taken seriously by health professionals.

Multiple Terms for the Condition

Once patients received a correct diagnosis, they faced problems due to CRPS still being known by outdated names. When Carolyn was diagnosed, *"it was called algodystrophy"*. She said, *"they still don't know CRPS in my local hospital"*.

The health professionals recognised this issue and as stated by HP1, *"even now, 25 years later, there are clinicians out there who still call it RSD."*

Poor Health Literacy of Patients

Some patients may have poor health literacy and therefore do not understand medical terms. The participants who were diagnosed as children stated they did not want to access information because they were afraid to face what might be ahead of them, while those diagnosed at an older age described being unable to discern good from poor information.

Receiving and Acting on Poor Advice

Diagnosis did not always result in correct advice and information from those HPs with little CRPS experience. As a child when diagnosed, Hannah recalled her doctor saying, *"I was too young for medication"*. She said, *"When we saw the doctors, they didn't really know what to do with me."*

As a majority of patients have minimal access to peer-reviewed research literature, the internet becomes a source of information, guidance, and peer support. The information provided, however, is not necessarily correct and can

be quite dangerous if followed. An example from Facebook is *"rub sandpaper on it to bring on remission."*^{49, 58}

Psychological Response to Symptoms

The majority of patient participants described what appears to be a psychological response to the development of CRPS symptoms. The majority described being more emotional than usual and losing self-confidence. Colleen said, *"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."*

Theme 2. Building an Armoury Against A Moving Target

Once patients have been diagnosed, they begin forming plans to live with the condition whilst becoming aware that CRPS changes over time. In the context of this research, the 'armoury' is every intervention a patient tries to improve their health. CRPS is defined here as a 'moving target' due to the changeable nature of the condition. Participants revealed that what is possible one day is not necessarily possible the next day. The moving target will be discussed first.

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 following injury, surgery, illness, tiredness, or stress. This phenomenon is often considered to be a *"spread"* by the patient and according to some participants, spread occurs seemingly without reason and can be extensive. Alice described her condition spreading from *"one leg to the other leg, and then involving both hips, arms and hands, lungs, digestive system, and teeth"*. As explained by HP1,

"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"

Fear of spread is a frequent topic on the internet. 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 rather than in the interviews, although participants still reported concerns.

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. (...) I wish it just stayed in my arm; I really do. Fred

Medication can Cease to Have an Effect

As CRPS changes, so too do the effects of medication. Medication increases were required by participants for many reasons including tolerance, illness, and stress causing an increase or change in the experience of pain. In some cases, unfortunately, the medication ceased to have an effect and alternatives had to be found.

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

In finding alternative medications or treatments, people with CRPS and their healthcare providers build an armoury of interventions as shown in the next subthemes.

Exploring Treatment Options

As there is no dedicated treatment, many participants found themselves accessing a large number of health professionals and were prescribed copious amounts of medication. Table 3 lists some of the treatments and medications mentioned by participants. This list is not exhaustive, as direct questions about the number of medications they took and treatments they underwent were not asked. The table gives the reader an appreciation of the number of health-related appointments and treatments the participants mentioned in their interviews. As said by Paul, *"I'm tied to medication. I take 32 tablets a day with my pain relief, and I'm on some very, very powerful stuff."*

Many participants described visiting both mainstream and alternate therapists and spending large amounts of time and money in the process. Jackie was desperately searching for a cure when she was interviewed four months after developing symptoms. She was attending both public and private physiotherapists, receiving four treatments each week. Additionally, she said:

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. Jackie

Surgical interventions were considered after exhausting oral medication and physical therapy options, with spinal cord stimulators being the most common. Although none of the interview participants had required an amputation, blogger Victoria underwent bilateral above-knee amputations and remains unable to wear prosthetic limbs due to continued pain and hypersensitivity. Many interview participants and contributors to the book had considered it as a possible option but understood like Paul 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."

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Finding the Balance between Quality of Life and Side Effects of Medication

Finding the balance between pain management, medication side effects, and quality of life was an issue for many of the participants who spoke of weighing up their choices. For example, some participants spoke of knowing that stronger pain killers would stop the pain, but the side effects of the medication would cause problems such as an exacerbation in constipation problems or an inability to safely drive a car. For Mel, this *"impacted on getting the kids to and from school."*

Females were especially concerned with weight gain once commencing Pregabalin (Lyrica), with gains between 15 to 27 kg in the patient interview cohort. This weight gain 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"*, particularly when tired, was another major side effect mentioned often in all sources. Terms used in the book include *"zombie"* and *"zonked out"*. Muddled thinking affected participants' abilities to work or study, and their ability 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 all *"too hard"*. Supportive partners were helpful. As Martin stated, *"my wife fills in the blanks."*

Theme 3. Battles Within the War

Wars consist of several battles. If CRPS is the overarching war, then various challenges are battles within the war. While each patient faces their own unique battles, some problems such as dealing with the initial pain and loss of function, financial issues and accepting a new normal appear to be fought by all.

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. This loss of function is frustrating particularly for those who previously led full lives. For example, Martin related how he was suddenly unable to go to the gym and could not do his usual running 20 to 30 km a week or cycling but felt that selling his bicycle was *"like giving up."* Karen recounted a trip to the dentist and shops. Describing returning home and the next day, she said:

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? Karen

Patients often require extended sleep and day naps following busy days, yet night-time sleep is often a problem and *"painsomnia"* which means not sleeping due to pain is a commonly used term on Facebook.

Table 3. 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	
LS block‡	X		X			X											
SC stimulation§	X		X			X			X								
Ketamine	X		X		X												
Capsaicin			X														
Botox	X					XX											

NOTE. X indicates the number of treatments or medications.

*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

Activity Pacing

Patient participants reported being taught by physiotherapists and occupational therapists to pace themselves by doing small amounts of an activity at a time. There was difficulty described by all participants from all sources including those who had long term CRPS in stopping before pain starts particularly when having a 'good [low pain] day.'

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 versus Causing a Flare

Some participants had also been advised by various health professionals 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 activity pacing, participants found it difficult to limit activities during a good day to not overdo it and cause a flare. This difficulty was often due to reverting to habits formed before CRPS and/or non-acceptance of the CRPS diagnosis and the "new normal."

Guilt

Over-exertion was often the cause of guilt as it resulted in increasing the burden on partners and family members. Other causes of guilt related by participants included no longer working and contributing financially to the household income and no longer performing household chores such as cleaning or mowing lawns. As Karen said, "You don't feel like you're pulling your weight." Guilt also came from being the cause of changed plans such as suddenly not being able to go out socialising.

Loss

Participants dealt with the loss of mobility and independence, and also loss of friends and jobs while coming to terms with the loss of their former body. Of the 17 patient participants, 11 had given up work and two had changed jobs due to their condition. Only two participants 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

Cloggy in the book describes a double loss and is quoted as saying "They weren't friends. They were workmates, which I thought were friends."

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Financial Considerations

Changed employment circumstances combined with paying for medication and private health practitioner appointments had a big financial impact. Private health care was not sustainable for most participants, but they described long waiting lists for most public health services. Concerns were voiced that participants could not access practitioners such as massage therapists due to the cost involved, despite the health benefits following this 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.

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

Insurance claims were considered a very stressful process for little financial gain and hardly worth the stress. There was an increased financial burden on most participants families and obtaining a disability pension was described as extremely difficult and stressful.

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

Judgement from Others, Such as Disbelief of Pain

Describing the pain was difficult (even when using a number out of 10).

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 ... trying to tell someone the magnitude of the pain! Sharon

Participants were disbelieved about their pain levels in hospital environments, further affecting their psyche.

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 I have. ... 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 for some patient participants, even being believed about pain intensity did not necessarily result in better care, particularly in the emergency department.

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. ... They're just going to think you're a drug seeker, like they don't help you. Jasmine

Theme 4. Developing Battle Plans with Allies

Patients require support to live with CRPS, but it does not necessarily come when or where expected. Some participants had to look outside the home for support and found health professionals with CRPS expertise difficult to locate. Participants described multiple appointments with a wide variety of HPs. Table 4 provides an indication of how many different HPs 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.

Patients Must Often Advocate for Better Treatment

Finding knowledgeable health professionals was described as a difficult process. Prior to learning more about their own condition, participants felt they did not know initially if their practitioner was appropriate for them. Referrals to pain clinics were not always forthcoming and participants also recounted experiencing refusals of second opinions which caused stress and exacerbation of symptoms. Some participants were fearful of advocating for themselves as they were in such a vulnerable, dependent position.

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 (lost) without you. Sharon

The Value of Multidisciplinary Health Care Teams

Participants felt that support was more forthcoming when the HP understood their pain levels and knew to ask before touching an affected body part. Usually, such knowledge was found in pain management centres with multidisciplinary teams, and participants who attended them often described receiving holistic support dealing with pain and issues of daily life. Pain psychologists or psychiatrists (specialising in pain), in particular those with good CRPS knowledge, were considered valuable sources of support by participants. Health practitioners also recognised the benefits of a multidisciplinary team "where you include the psychological pain management component".

Family Support

Many participants relied on family members for support and some found novel solutions to encourage participation in activities. For example, Carolyn's family

Table 4. 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		XXX	XX		XX	X			X			X	XX
Physiotherapist	XXX	X	X	X	X		XX	X	X		X	XX	X		X	X	
Occupational therapist				X			X						X	X			
Psychologist General	XX	X		XX	XX	X	XX		X		X		X	XX	X	X	X
Practitioner Pain specialist	X	X	X	X	X		XX	X	X		X	X	XX	X	XX	X	
Exercise Physiologist	XXX	XXXX	XXX	X	XX	X	XX	X	X		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. Each X indicates a separate health professional seen by the patient participants.

members walked on her affected side when in public to protect it from being bumped.

Finding Support Outside The Family

Participants revealed mixed feelings regarding internet groups, stating that while catastrophising seems to be worse on closed Facebook sites, other internet groups foster friendships – or allies, and members continually swap helpful information.

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. (...) Karen

Theme 5. Warrior or Prisoner of War

The word warrior is often used in conjunction with fighting illness by the general public. Participants spoke about defining themselves in an altered body and feeling vulnerable, or alternatively, 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 with participants feeling as though they were 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.

Hiding behind a Mask

There were many reasons participants did not disclose their pain levels. Some pretended to be better than they felt because *'to give in would mean to break down and lose control'*. For others, it was a mechanism to protect those around them from the pain of seeing a loved one suffer. Others wanted to appear normal and not stand out in a crowd. *"When you're a kid you try and hide anything that makes you different from other kids"* said 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. Most participants described difficult times and times of depression and/or anxiety particularly in the early years following diagnosis. Different techniques were used by participants to change their attitudes to become more positive, including reinventing themselves, forgetting old abilities and focusing on *'what can I still do'*? Such attitude change from being a prisoner of war and becoming a warrior was acknowledged as *'treading a thin line'* by Dianne who also said people in pain *"require support to keep positive and engage with life."* Assisting patients to activate resilience factors can be a

Patients Describe their Lived Experiences of Battling to Live challenge and when discussing the term CRPS warrior, HP1 felt that *"it is nice in a way because it's like trying to take some power over the condition."* HP3 agreed, saying *"battling it and being a warrior is entirely appropriate."*

Once participants had their condition under control and felt mentally strong, they often wanted to raise awareness of CRPS. The patient-run initiative colour the World Orange Day [<https://www.colortheworldorange.com/>] was mentioned more than once.

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 (...) Sarah

Confronting Problems

Participants often had unique approaches to solving problems and solutions found for everyday issues included adapting self-care tasks, doing all shopping on the internet, and home delivery of groceries or ready-made meal plans. Problem-solving approaches to household chores encompassed leaving it not done, paying someone, or asking for help from family members. Men in this study were particularly frustrated that they could not manage to mow their own yards, which they interpreted as not fulfilling their male role. In contrast, female participants did not designate themselves particular household roles. Those participants unable to self-care faced issues such as the health or age of their carer, and in the cases where the carer was not a family member, trusting that person was a problem.

The Prisoner of War

Each participant described a difficult time when they were unable to function properly. The 'prisoner of war' mind-set of having no options or control was experienced by all participants for varying lengths of time. Fred told of a time when *"I didn't know where else to go or what to do."*

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.¹⁷ The interviewed HPs' 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 interview participants disclosed suicide ideation in the past, none admitted actual attempts. The stories of Sarah and Thomas in the book mention their suicide attempts.

Discussion

Qualitative research is an avenue to provide better understanding of CRPS^{12, 32, 34} and a better understanding of lived experience of pain creates the potential to improve clinical pain management by enhancing comprehension and empathy from clinicians.⁶⁴ It was expected that understanding and destigmatisation of people living with CRPS might be increased if people who do not live with chronic pain gained an appreciation of the daily struggles faced by people who do.²⁴

The aim of this research was to better understand the phenomenon of chronic pain from the lived experience perspective of people living with CRPS. It was seen by patients as a difficult war-like experience or a battle. The research themes have been collated in a visual framework using the orange awareness colour mentioned by Sarah (Fig 3).

As the literature generally acknowledges that early diagnosis and treatment lead to better health outcomes for patients,^{27, 38, 47} the lead time to diagnosis likely impacted the level of disability and pain experienced by patient participants in this study. CRPS duration, length of time to diagnosis, educational level or living arrangements though, had no bearing on which elements of the battle theme best suited participants. Some disclosed willingness to travel long distances to consult HPs based on peer recommendations however even patients attending specialist pain centres experienced delayed diagnosis; the worst case being nine years. The accounts of delayed diagnoses support the notion that CRPS can be referred to as an unseen enemy.

Similar to the 'quest' as stated by a participant in this study, delayed diagnosis was also reported by Binkley⁴ and Ott and Maihöfner,⁴⁷ and Grieve et al.²⁷ reported that lack of awareness of CRPS diagnostic criteria and

clinical guidelines by some HPs leads to a risk in misdiagnosis and inappropriate management for some patients. In this study, participants provisional diagnosis of CRPS was most often made by a physiotherapist or doctor. Formal diagnosis was made or confirmed by a doctor specialising in pain medicine, orthopaedics, or rheumatology. All but one participant had seen at least one pain medicine physician at the time of interview.

Long waiting times to see a specialist impacted study participants as likewise reported by Binkley⁴, who stated that mechanisms to ensure prompt assessment for all CRPS patients should be in place. Furthermore, United Kingdom guidelines propose diagnostic improvements be made with healthcare professional training and state that patients demonstrating a lack of improved function and no pain reduction should be referred to specialised CRPS care within two months of commencing treatment²³. Continued use of outdated terms such as Reflex Sympathetic Dystrophy (RSD) instead of CRPS was noted as a confounding factor by participants which according to Borchers and Gershwin,⁷ has misguided treatment and research for decades.

Further adding to the confusion, some people have combined the terms and RSD/CRPS or CRPS/RSD can be found on many internet sites such as those selling awareness items, blogs, and Facebook. This is the information that the general public, and patients prior to diagnosis, are most likely to see and believe. (Examples may be seen at <https://www.amazon.com/CRPS-Awareness-Shirt-Warrior-Fighting/dp/B07FH8C823> which sells awareness items, Pinterest <https://www.pinterest.com.au/nada1970/crpsrd-for-my-daughter-the-crps-warrior/?autologin=true>, and support/information sites such as <https://rsds.org/telltale-signs-and-symptoms-of-crpsrd/> and <https://www.practicalpainmanagement.com/>

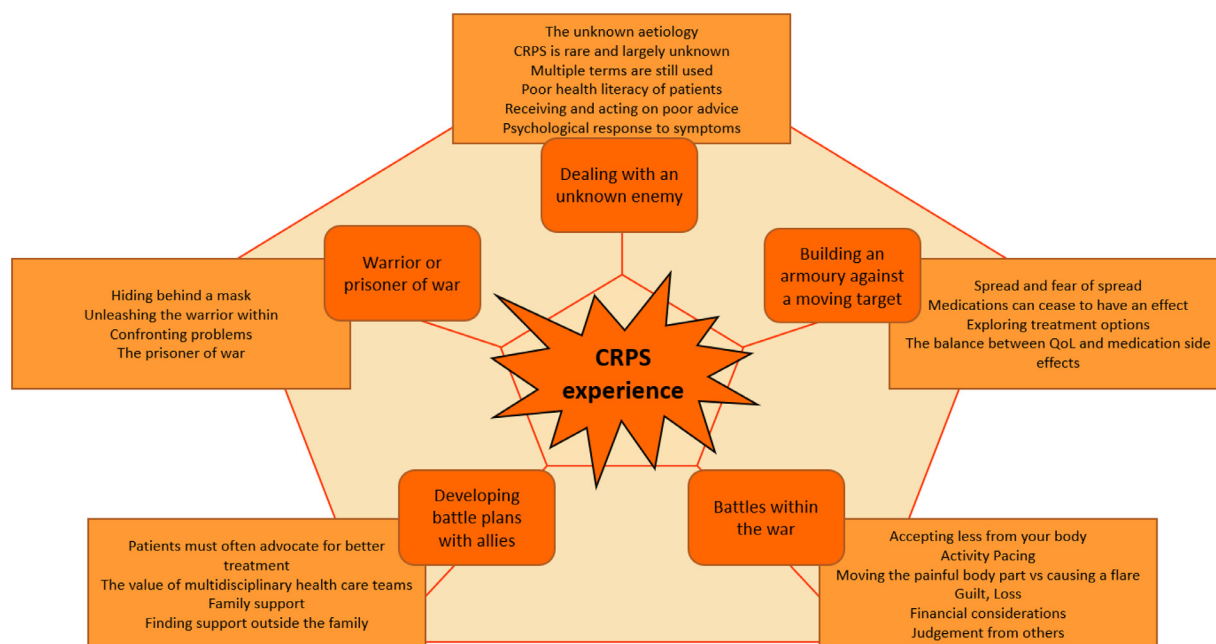


Figure 3. The lived experience of CRPS.

[patient/conditions/crps-rsd/crps-rsd-overview](#)). It must be noted that no criticism of these sites is intended.

Previous research investigating CRPS knowledge and information requirements,^{10, 25} and current research investigating information seeking behaviour in the context of COVID-19⁵⁷ report similar findings that patients and the general public primarily seek information from the internet, mass media and social media and have generally not undertaken health literacy training. Non-academics may often struggle to access academic papers⁵⁰ and therefore, many people do not engage with academic research literature, and do not understand medical terminology or research findings. Although there are excellent internet sites in existence, 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 causes CRPS,³³ and Pregabalin (Lyrica) causes brain damage.¹⁶ Such notions can exacerbate the anxiety and emotional distress experienced by patients who are unable to examine information credibility,⁵⁷ which can not only sustain pain but also be a consequence of pain.⁸ As demonstrated, there is an emotional response to living with the initial symptoms of CRPS, although it is rarely acknowledged in the literature.

The second theme incorporated the knowledge that there are no dedicated medication or treatment to manage a condition that can move to include other body parts. The possibility of disease spread is a common battle for patients and can be a contested issue amongst health professionals. CRPS is known to spread to other body parts in up to 50% of patients with contralateral or proximal spread being the most common.^{3, 11, 32} While the underlying neural mechanisms are the focus of current research into this phenomenon,¹¹ according to some participants, spread occurs seemingly without reason and can be extensive. CRPS is diagnosed using the validated 'Budapest Criteria'^{5, 9} which requires self-reported symptoms and clinician observed signs. Thus, the diagnosis of internal organ CRPS such as in the intestines or lungs is impossible, however, some patients believe they have CRPS internally, despite the opinion of health professionals.

In the absence of quality evidence for or against the effectiveness of any CRPS intervention, Bruehl⁸ suggests that the collective expertise of other clinicians should guide the clinical care of patients. Promoting an understanding of pain and acknowledging pain and suffering of the patient with rehabilitation has been proposed as a treatment approach.⁴³ Pain rehabilitation as a biopsychosocial approach to pain management as opposed to the clinician working from the medical model should empower patients with knowledge, understanding and skills.⁴³ While Goebel et al.²² believe rehabilitation should be delivered by occupational therapists and/or physiotherapists, they make no mention of alternate therapies such as massage, which was considered helpful to some participants in this study. Additionally, Sale and Thielke⁵² believe that qualitative research is fundamental to evidence-based medicine and the values and

Patients Describe their Lived Experiences of Battling to Live preferences of the patient are the foundation of scientific knowledge.

While concepts of guilt, loss, financial considerations, pain coping and reduced activity are well documented in the CRPS literature,^{4, 32, 44, 48} this study identified that HPs rarely know of daily battles (within the CRPS 'war') faced by patients such as finding the balance between moving the painful body part to maintain function while not causing a flare. The knowledge that pain does not equate to damage as described by Lotze and Moseley⁴³ is a difficult concept to grasp and unconscious safety-seeking behaviours can be difficult for both the patient and HP to recognise and monitor.

The participants in this study shared their belief that HPs often want to quantify pain intensity as evidenced by the development and use of pain scales such as the numeric rating scale. Whilst pain scales are useful tools particularly for acute pain³⁶, CRPS pain and subsequent physical limitations can change throughout the day; therefore, participants felt it was impossible to provide a number out of 10. Such scales do not recognise the debilitating effect of a continuous pain score of three or four when combined with additional confounding issues such as loss of function, inability to sleep, and financial, emotional, or psychological issues such as those described in this study. Pictorial versions of the McGill Pain Scale^{1, 59} are often posted on CRPS support group websites and many participants were aware that this scale defines CRPS as the worst pain known to man. Some HPs saw that as a sign of patients distress or catastrophising. Participants also stated that they found it difficult to describe or express their pain but had never completed the McGill Pain Questionnaire or the Short-Form version (SF-MPQ-2).³⁶ HPs need to consider CRPS pain severity along with factors such as quality of life, pain impact, participation and psychological function and the core outcome measurement set for complex regional pain syndrome clinical studies (COMPACT) registry seeks to do this.²⁶ It includes the SS-MPQ-2³⁶ and the CRPS Severity Score,³⁰ recognises the multidimensional nature of CRPS and is aiming to facilitate appropriate quantifiable data collection regarding CRPS pain and severity.²⁶

The theme developing battle plans with allies, involved finding support to manage CRPS. Though not evident in this research, Keogh and Herdendorf³⁷ assert that women in pain are more likely than men to find alternate coping strategies and it has been suggested that men may benefit from training in emotion-based coping strategies.¹⁸ Fulfilling traditional gender roles though, were a specific issue for males in this study and inability to properly parent was an issue leading to feelings of guilt for both men and women. Changing family roles in this study were similar to previous findings of experiences of people living with fibromyalgia and rheumatoid arthritis.^{2, 14} Experiences described in this research were also reflected in role changes and self-preservation described by Packham et al.⁴⁸

Those participants attending a multidisciplinary clinic or who found supportive peers and knowledgeable

health professionals were more likely to report better health care, better health outcomes and demonstrated more resilience than those who did not which are concepts well supported in both past and recent literature.^{4, 15, 21, 45} Patient-centered care was not always evident however and a paternalistic approach was also found in a recent international survey as reported by Grieve et al.²⁷

Most participants used the internet for information and support, particularly before diagnosis, but reported it as both helpful and a cause of distress. Catastrophising posts particularly about CRPS spread and worst-case scenarios can be more prevalent than posts about good health outcomes.^{51, 56} The provision by HPs of a list of helpful sites to patients might be useful in reducing cyberchondria²⁰, but patient understanding must be ensured.

CRPS has an uncertain outcome and health professionals need to balance outcomes and guide patients to develop a sense of coherence and resilience factors to aid in improving quality of life.^{27, 66} Additionally, changing the narrative regarding people living with CRPS from stigmatising terms such as 'sufferers' to 'warriors' may change the model of clinical engagement from negative stereotyping to one of empathy, validation, and inclusion in the pain management process.¹³ The HPs interviewed regarded the adoption of a warrior attitude as appropriate and supported the use of the term warrior. While the term 'prisoner of war' was not used in the interviews, all participants recognised the need to develop coping strategies and resilience.

Implications for Practice

Many HPs have limited knowledge about rare conditions such as CRPS⁸ and should be encouraged to ask for second opinions or refer patients with previously unencountered symptoms quickly to aid in more timely diagnosis.²⁷ As found by Ten Brink et al.,⁶⁰ most participants in this study were provisionally diagnosed with CRPS by a physiotherapist. Goebel et al.²³ recommended that education in basic methods of pain (including CRPS) rehabilitation be given to physiotherapists and occupational therapists and the authors suggest CRPS information based on patients lived experience should be included in the undergraduate education of all HPs.

CRPS patient voice is recognised as important via the inclusion of patients on research teams and task forces.^{8, 22, 28, 42} It was used to generate the lived experience model (Fig 3) which could be a resource for both patients and HPs. It highlights patient issues which are not readily recognisable to most HPs. The model appears useful regardless of the duration or chronicity of disease as each participant described experiences contributing to each theme during their interview. It may help to determine which particular areas the patient requires support. Each point within the themes could be used to prompt discussion and guide care but further research may be required to determine if the battle terminology remains appropriate in clinical care. Use of the model may ensure referrals to other

specialists as necessary and a shift from symptom-centered to true patient-centered care.

Further research is proposed in which a program of CRPS education is offered and introduces the model to nonhospitalised patients and health professionals working in the community. The aim is to determine if use of the model empowers patients to ask for extra support and to assess if health professionals demonstrate an increased understanding of CRPS from the patient perspective. If successful, the program would be expanded to include patients and health professionals in a hospital and/or rehabilitation setting. Planning for such a study has yet to be undertaken.

Strengths and Limitations

Multiple data sources and methods were used in this research to ensure data triangulation and rigour. Open internet sites, patient stories from a book and health practitioners were accessed along with patient participants. There was a range of ages and CRPS duration amongst interview participants, and a mix of disease severity and progression. The first author disclosing her CRPS diagnosis resulted in the development of a strong rapport and deep understanding with participants. All participants, however, were Anglo-Saxons in high-income countries with similar health care systems which limits the generalisability of this research beyond these settings.

The fact that closed internet sites were not accessed for this study could be considered a limitation because people considering themselves cured or in remission are not represented.

Conclusion

Pain is a complex phenomenon that manifests in different ways in different conditions and individuals and is closely involved in the quality of life of these individuals. This becomes further complicated in the case of CRPS where pain and physiological symptoms need to be considered concurrently with the original precipitating injury. This study provides a better understanding of the experience of living with CRPS and could influence the way management and interaction with persons with CRPS is conducted in the future.

Better CRPS treatment can result from better understanding the lived experience of patients. People with CRPS who get appropriate health care report better pain control and improved health outcomes. Patients can be a valuable member of the healthcare team treating this condition and are keen to participate in raising awareness of the condition and building their own treatment plans. Such partnerships result in self-management and improved quality of life through education of HPs, better communication between professionals and patients and through client empowerment. The model proposed provides useful insights for HPs and patients alike.

Acknowledgments

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. There are no conflicts of interest to declare.

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Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jpain.2021.03.151>.

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