



Topical review

Building the evidence for CRPS research from a lived experience perspective



Colleen M. Johnston*, Florin I. Opreescu, Marion Gray

School of Health and Sports Science, Cluster for Health Improvement, University of the Sunshine Coast, Australia

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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* Corresponding author at: University of the Sunshine Coast, Faculty of Science, Health, Education and Engineering – ML39, University of the Sunshine Coast, Locked Bag 4, Maroochydore DC, QLD 4558, Australia. Tel.: +61 7 5445 0652; fax: +61 7 5459 4880.

E-mail addresses: Colleen.Johnston@research.usc.edu.au (C.M. Johnston), foprescu@usc.edu.au (F.I. Opreescu), marion.gray@usc.edu.au (M. Gray).

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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.

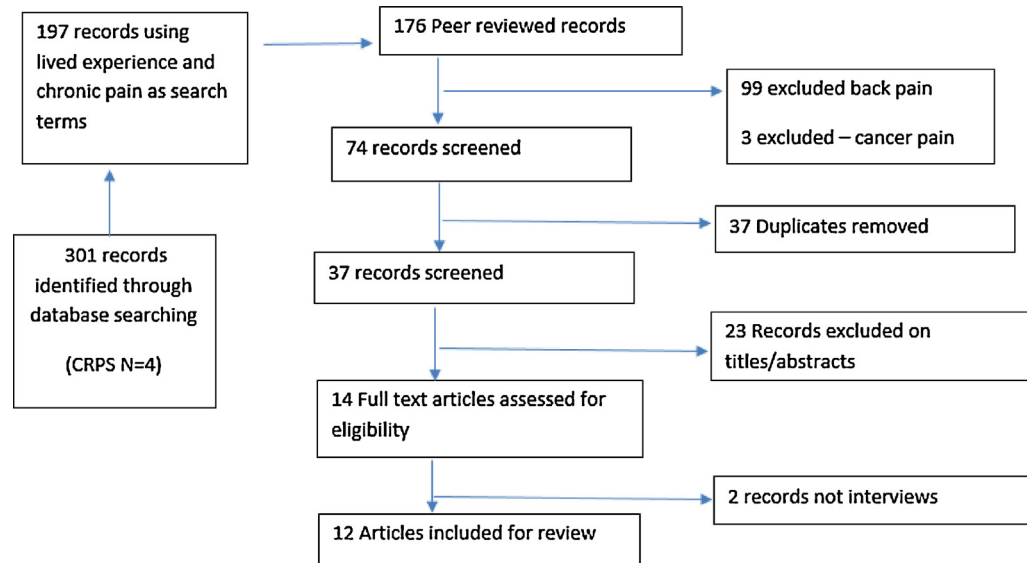
This model depicts themes emerging from the data on living and dealing with constant pain – the disbelief other people have of the symptoms, loss of the former healthy body, job, friends, lifestyle, the non-compliant, constantly painful body, self-management, treatment and alleviating pain [4,10,12,13,35].

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

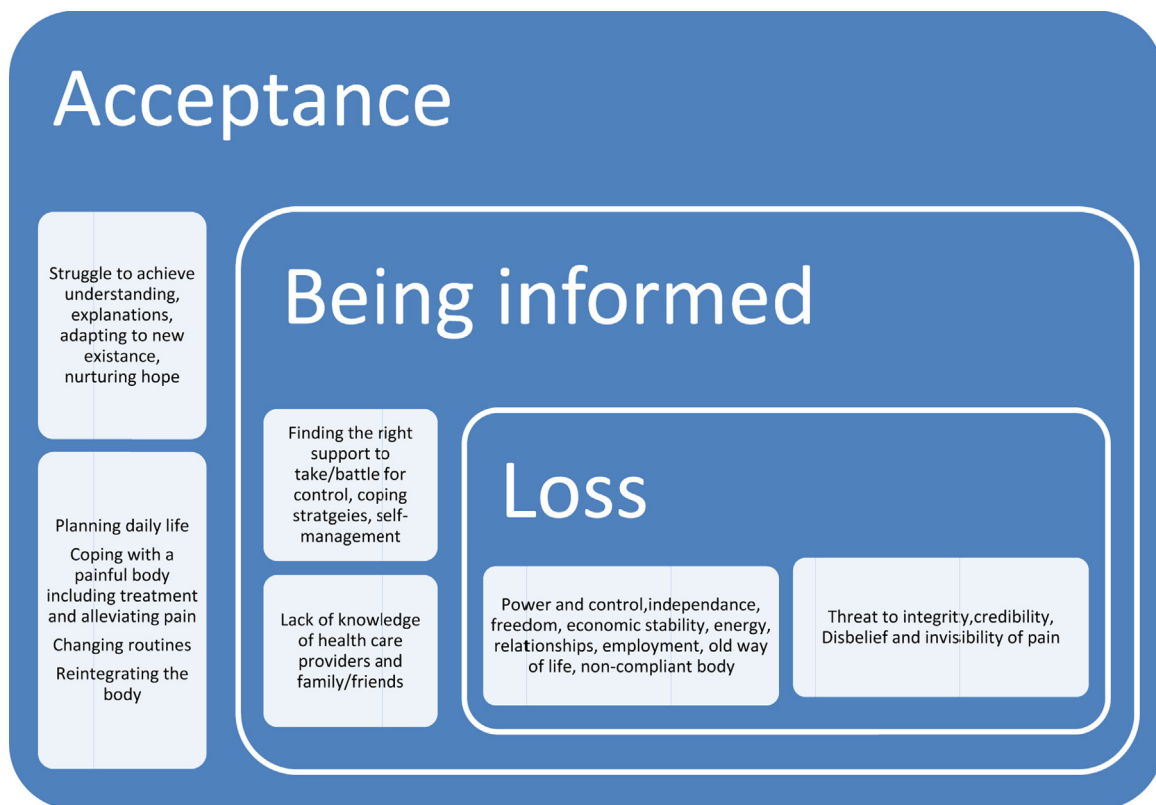


Fig. 2. Proposed model of lived experience of chronic pain.

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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** 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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