

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

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Introduction

Complex regional pain syndrome (CRPS) is frequently considered a limiting and distressing condition, and previous research has focused on the difficulties of living with CRPS and the shortcomings of healthcare and society. However, there is considerable variability between individuals with CRPS, and some people with CRPS maintain employment and lead meaningful lives despite their condition.

To our knowledge, no study has attempted to understand how people learn to live well despite experiencing long-term CRPS. This information could inform the development of future resources.

Aim:

To understand how individuals with long-term CRPS live well despite their pain.

Participants

Purposive sampling was used to recruit 10 adults with:

- Complex Regional Pain Syndrome
- Symptoms >12 months duration
- Who self-identify as “living well”

Methods

Semi-structured interviews explored:

- Personal experiences of CRPS
- How they were living well
- Sense-making processes

Analysis

- An interpretivist philosophy was used to focus on experiences and sense-making
- The six steps of Reflexive Thematic Analysis (Braun & Clarke) were followed to code interview data and develop themes.

Findings

Participants (N=10, 70% female, age 23-82, CRPS duration 2-16 years) described living well with CRPS as the result of a journey, and acknowledged previous times of not living well: “Living *against* CRPS”.

Living *against* CRPS was characterised by symptom dominance, a loss of physical function, emotional distress, altered body perception, and a disrupted sense of self.

In contrast, participants described “**Living Well with CRPS**” as having a restored sense of purpose, meaning and new identity, and accepting the focus on living alongside their painful limb. The three themes which described how participants lived well with CRPS are shown in Figure 1. These involved making sense of a new life with CRPS, taking control in a seemingly uncontrollable world, and rebuilding a purposeful life with a new identity.

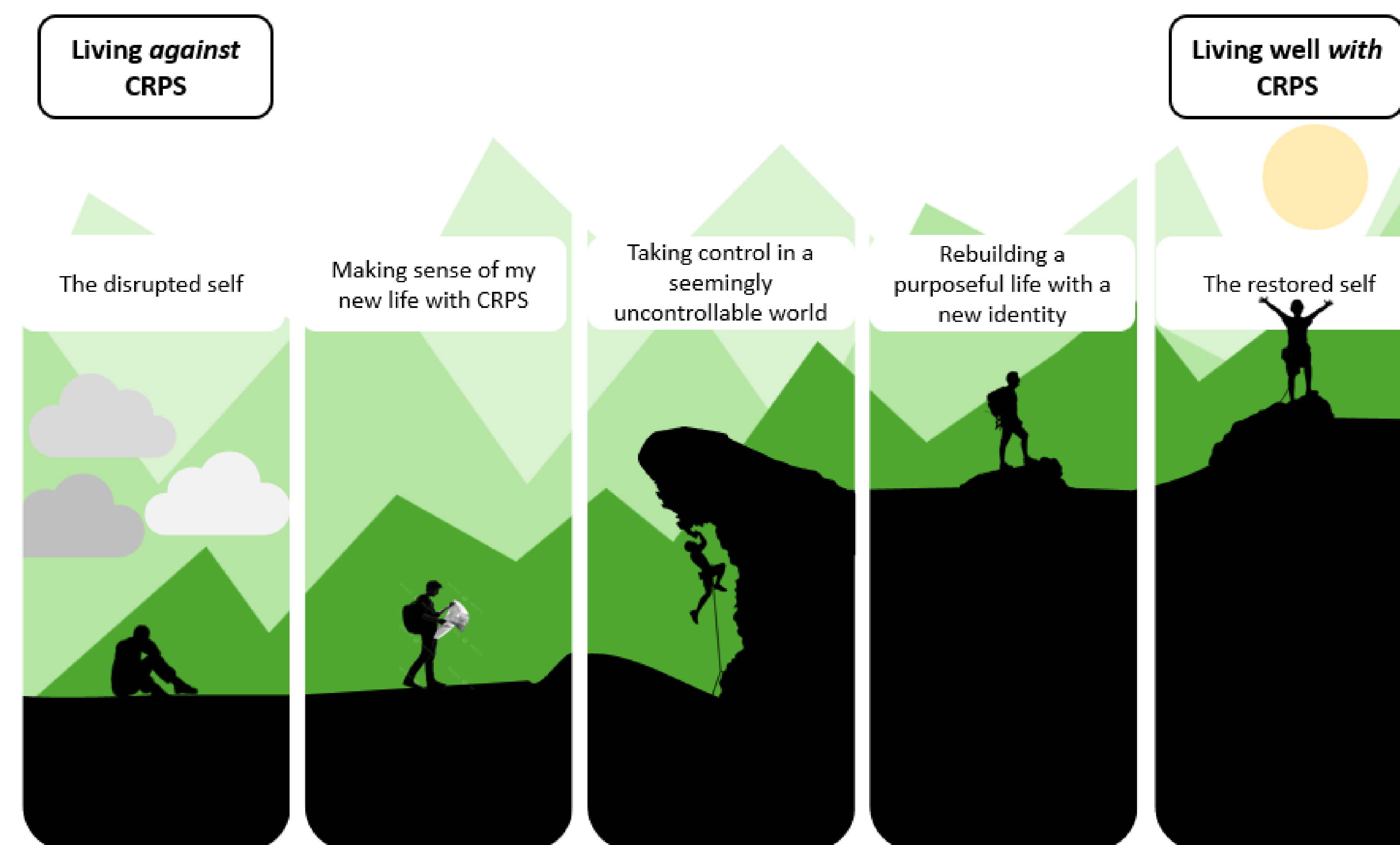
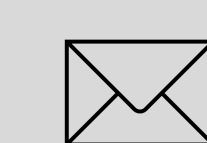


Figure 1. Diagram demonstrating three overarching themes describing Living Well with CRPS

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Theme 1: Making Sense of My New Life with CRPS

- **A Diagnosis:** provided a way to make sense of the symptoms and gather information, and validated the legitimacy of symptoms. *“to know it's not in my head. So just getting that diagnosis was like, hallelujah”*
- **Information & Support of Others:** information online was often negative but reliable information was valued. Meeting other with CRPS was described by many. *“It's good to be able to identify with somebody else. Then you don't feel so alone in the process”*
- **Developing a Sensemaking Model:** Many adopted a neurobiological model to understand CRPS. The specifics of the model were not important so long as it allowed them to take control. *“It's like your central nervous system... becoming hypersensitive and exaggerating your senses.”*

Theme 2: Taking Control in an Uncontrollable World

- **Professional Support:** Experienced, knowledgeable, empathic clinicians were valued. *“they saw me as a person. They knew what CRPS was, and they were understanding of that.”*
- **Evaluating Tools of Self-Management:** Tools such as medication, cognitive strategies, graded physical activity, and self-care were individually evaluated for helpfulness and adopted or rejected accordingly. *“If I don't take care of myself, I will be back at square one and I won't be able to do the stuff I really enjoy”*
- **Recalibrating a new Pace of Life:** Consciously slowing down activities and being more selective with finite activity levels was described by all participants. *“Not soldiering on... actually listening to your body”; “patience”; “to chill a bit more”*

Theme 3: Rebuilding a Purposeful Life with a new Identity

- **Accepting my New Life with CRPS:** involved a perspective shift to live well with CRPS and focus on restoring purpose over pain elimination. *“if they can actually accept that it's going to be there for the rest of their life, they can then build their life around it... and still be productive and everything else like that”*
- **Restoring Purpose & Meaning:** by maintaining and restoring some of the activities lost due to CRPS, usually with necessary adjustments. *“Like, I go to [my kids'] sports... I've got one of those mini fold-out chairs. So watching the kids' sports, you know? That's pretty massive, the kids knowing that I care.”*
- **Reconstructing a new post-CRPS Identity:** the process of deconstructing and reconstructing their pre- and post-CRPS identities gave participants an opportunity to redefine themselves. *“actually, I became a better person... It doesn't define me.”*

Conclusions:

- People make sense of CRPS and its impact in diverse ways
- People with CRPS want to take control of their recovery
- Living well with CRPS is about restoring a sense of meaning and purpose