









Understanding the biopsychosocial impacts of living with Complex Regional Pain Syndrome

Alison Llewellyn^{1,2}, Mary-Jane Sweeting³, Candy McCabe^{1,2,4}

¹Department of Nursing and Midwifery, University of the West of England, Bristol,

²Complex Regional Pain Syndrome Service, Royal United Hospitals Bath NHS Foundation Trust, Bath,

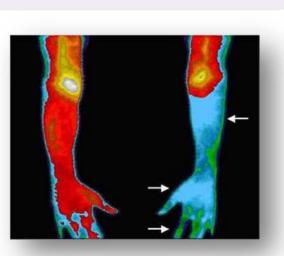
³Therapies Service, Gloucestershire Hospitals NHS Foundation Trust, Gloucester, ⁴The Florence Nightingale Foundation, London

Aim of the investigation

- Complex Regional Pain Syndrome (CRPS) is a disabling chronic pain condition, commonly triggered by trauma to a limb.
- Amongst its characteristics are:
 - severe unremitting pain
 - autonomic, motor and sensory changes
 - disrupted body perception^{1,2}.
- While CRPS signs and symptoms are well documented, the wider biopsychosocial consequences of living with CRPS have received less attention.
- Understanding the broader impacts has important implications for treatment and rehabilitation services.







Methods

- In a previous study, participants (≥18 years) who met, or had met, Budapest diagnostic criteria for CRPS¹ were recruited via databases and clinics in eight countries in order to define recovery from CRPS from the patient perspective³.
- In free text responses, participants however also described the wider biopsychosocial impacts of the condition.
- The current study presents results from a secondary qualitative analysis of these latter data, using inductive thematic analysis to identify the biopsychosocial impacts of the condition.

Conclusions

- These findings highlight the multidimensional nature of the biopsychosocial impacts of CRPS.
- Clinicians should be mindful to use personcentred approaches in which the impacts of therapeutic interventions for CRPS on psychological wellbeing are considered, as well the effects on physical function outcomes.

Working Matters Together Difference

Email:
Alison.Llewellyn@uwe.ac.uk
or Alison.Llewellyn@nhs.net

Results

Responses were received from 347 participants (80% female, 53% disease duration \geq 3 years). Five superordinate themes, and their associated sub-themes were identified:

"My life is very much within four walls"

"My family

didn't

understand

and still

doesn't" "

Life is less

- Restricted participation
- •Freedom and independence are reduced
- Negative impact on social relationships
- Then and now comparisons

"I am hoping to be able to return to normal as I was before the injury" "For now I am dependent on my family members for daily errands"

Identity is impacted

- •Reduced self-esteem
- Difficulty of maintaining social roles
- •Impact of changes in appearance

"[I want] a full night's sleep without being disturbed by pain"

.. because of

the medication I

cannot drive my

car"

Physical consequences

"I [want to

have] more

energy after

work for my

family..."

- Fatigue, sleep and cognition problems
- Consequences of medication side-effects
- Impact of motor impairment

properly without a stick or crutch. If the 'label' of feeling like a disability could be peeled away."

"I [wish I] could walk

"I would feel more

alive, useful

without pain."

"I have weak grasp, objects frequently fall from my hand"

"I am always being bothered about being knocked which makes me worried so I tend to stay at home."

Psychological distress

- Experiencing negative affect
- Experiencing anxiety and depression

"I find I get depressed, my family shake me out of it ... but even then it's a struggle." shortest way to do an activity"

"[I] think of the

Coping Strategies

- Developing practical solutions
- Maintaining psychological wellbeing

"I try to be positive...because there is always somebody worse than me.""

Acknowledgements:

The data collection for the previous study, from which the present data were taken, was funded by the Reflex Sympathetic Dystrophy Syndrome Association and the Dutch National CRPS Patient Association.

References

¹Harden, R.N., Bruehl, S., Perez, R.S., Birklein, F., Marinus, J., Maihofner, C., Lubenow, T., Buvanendran, A., Mackey, S., Graciosa, J. and Mogilevski, M., 2010. Validation of proposed diagnostic criteria (the "Budapest Criteria") for complex regional pain syndrome. Pain, 150(2), pp.268-274.

²Lewis, J.S., Kersten, P., McCabe, C.S., McPherson, K.M. and Blake, D.R., 2007. Body perception disturbance: a contribution to pain in complex regional pain syndrome (CRPS). PAIN, 133(1-3), pp.111-119.

³Llewellyn, A., McCabe, C.S., Hibberd, Y., White, P., Davies, L., Marinus, J., Perez, R.G.S.M., Thomassen, I., Brunner, F., Sontheim, C. and Birklein, F., 2018. Are you better? A multi-centre study of patient-defined recovery from Complex Regional Pain Syndrome. European journal of pain, 22(3), pp.551-564.