Defining recovery from Complex Regional Pain Syndrome.

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Aim of Investigation:

The longevity and complexity of symptoms in persistent Complex Regional Pain Syndrome (CRPS) leads to problems in defining recovery and evaluating the efficacy of therapeutic interventions. Using a 2-Round Delphi-based process, with an international sample to ensure population diversity, we sought to identify patients' definition of recovery; the qualitative themes they considered most important; and to understand the self-reported symptoms, demographic and bio-psychosocial factors that may impact this definition. A better understanding of patient-defined recovery is important for healthcare professionals in designing and evaluating future treatment approaches.

Methods:

Potential participants ≥18yrs who met, or had met, Budapest diagnostic criteria for CRPS, were identified from databases and clinics in 8 countries (UK, Netherlands, Germany, Denmark, Switzerland, Poland, Canada, USA). In Round 1 of the Delphi process, participants completed the statement "I would consider myself recovered if...". Data were thematically analysed and ordered under the WHO ICF classification, providing 62 statements representing the most frequently mentioned themes. In Round 2, the same participants were asked to identify and rank the 10 statements they considered most important to their perception of recovery. Cumulative weighted percentages identified the top statements overall. Participants completed demographic and symptom questionnaires and standardized measures for pain (MPQ), quality of life (QoL) (EQ-5D), psychological flexibility (AAQ-II), function (RSQ for upper-limb CRPS / WAQ for lower-limb). Data were examined using Chi-squared, Welch's t-tests, odds ratios and regression analyses.

Results:

Dominant themes for patient-defined recovery from 347 patients (80% female, 91% non-recovered, 53% disease duration ≥ 3yrs) were: activities of daily living; bodily functions (including CRPS symptoms and pain); external factors (including medication use) and participation (e.g. housework, shopping). Personal factors (anxiety, depression) were least represented.

The top five ranked recovery statements from 252 participants were: no longer having 1) CRPS-related pain, 2) generalised pain and discomfort, 3) restricted range of movement, 4) need for medication, and 5) stiffness in the affected limb. The top three statements of most subgroups (males, females, recovered, non-recovered, age groups 30-50 and 50+, paid employment, non-employed, all disease durations, upper and lower limb CRPS) were all within the overall top five.

Quantitative data showed self-reported recovery was associated with: number of reported symptoms (p < .001); knowing CRPS type; having caring responsibilities (p < .05). There were no associations with demographics, disease duration, trigger, or limb affected. Non-recovered participants had lower psychological flexibility, higher pain and lower QoL (p ≤ .001). Non-recovered participants with lower-limb
CRPS more frequently reported hyperalgesia, allodynia, hair changes, and involuntary muscle movements than those with upper-limb CRPS, and had poorer pain (p < .01), QoL (p < .05) and SF-36 physical functioning (p < .001) and energy/fatigue scores (p < .05). Function, psychological flexibility, and number of symptoms were jointly (p < .001) and individually (p < .05) predictive of QoL for non-recovered participants with upper-limb CRPS.

Conclusions:
Our data suggest a very small number of themes are of highest importance to people with CRPS in their definition of recovery and these vary little with demographics. Patients want their CRPS-related pain, generalised pain, movement difficulties, and medication reliance to be addressed, above all other factors, for them to consider themselves recovered.

Unresolved CRPS has negative consequences for mental and physical well-being, and the poorest health outcomes were found for people with lower-limb CRPS. Disease duration and demographic characteristics did not influence recovery status but a small "recovered" sample (9%) should be noted.

Pain in Specific Clinical Disease Entities:
Complex Regional Pain Syndrome