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Editorial comment

Qualitative research in complex regional pain syndrome (CRPS)

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There are two points for discussion concerning the article entitled "Building the evidence for CRPS research from a lived experience" in this issue of the *Scandinavian Journal of Pain* [1]. The first is: why do qualitative research? The second is: would qualitative research in complex regional pain syndrome (CRPS) really help patients and practitioners?

1. Why do qualitative research in patients with pain

To answer the first question, qualitative research (QualR) in medicine has a long track record although somewhat shorter in the area of pain. A search in PubMed using the search words "qualitative" "research" "pain" gives 3479 hits. A quick review of the first 40 articles shows that over half actually are on clinical pain syndromes and the process goes back several years. The structure and practice of QualR are both well established and comprehensive texts on this have been published as the authors point out [2].

Although often considered "not scientific" by those doing quantitative research, many in quantitative research in pain use methods derived from QualR. As the authors of this paper also point out, Ronald Melzack began developing the McGill pain questionnaire (MPQ) by talking to a patient with phantom limb pain on several occasions, fascinated by her descriptions of the pain [3]. The description by Melzack of the process makes interesting reading. His background as a part time author of lay literature perhaps was behind this interest in words but Melzack used a quasi-QualR technique and the MPQ that resulted now is routinely used in clinical pain research.

2. Patient reported outcome questionnaires (PRO)

The McGill Pain Questionnaire (MPQ) is one of a series of commonly used patient reported outcome (PRO) questionnaires and PROs as assessment tools are now required by both the FDA and EMA in Phase I–III pharmacological studies in pain therapy before official approval is given to market them. The PROs rely on subjects' report of their experience when taking the drugs and are semi- qualitative. In addition, some agencies require a "cognitive debriefing" of subjects involved in clinical trials which is a structured interview of a small cohort of those included in the studies, a QualR process. My opinion is that QualR has been useful in the past and can continue to contribute to our knowledge of pain patients.

3. Would qualitative research in CRPS really help patients and practitioners?

To answer the second question, could QualR help in studies on CRPS, the actual purpose proposed by the authors is somewhat vague. A recent QualR study in CRPS by Grieve et al. [4] indicates a lack of available patient education information in the United Kingdom and recommends establishing a support system with information for patients and this problem is alluded to by the paper reviewed here [1]. As they also state, more information on the "lived experience" of those with CRPS could relieve patient anxiety and make the healthcare system somewhat more sympathetic if it could be available universally. The crux of this problem is as the present authors point out – the diagnosis of CRPS is not generally recognized by the healthcare system and therefore patients and providers would not be aware of such information. This situation is similar to the problems surrounding other poorly understood chronic pain syndromes such as fibromyalgia and whiplash associated disorders. Many of the issues Johnston et al. [1] present in the discussion section are simply generic to chronic pain. Grieve et al. [5] point out in another article that the outcome measures now used to evaluate CRPS are varied and it is difficult to synthesize the current literature.

It is also possible that the symptom focus for present treatment is not what patients' consider the most important and a QualR study might find another focus for treatment that could be more meaningful for the patient. It could also help to unify outcome measures used in CRPS research so that more studies evaluate the same variables. This would be a real breakthrough since the focus on pain has not led to very effective treatments for the majority of patients.

The authors have formulated an outline for structured interviews of patients with CRPS [1]. This adds more detail than the study by Grieve et al. cited above [4]. I would also suggest adding further questions such as "What treatments have you had for your problems?", "Can you describe the symptoms you have that are the

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most bothersome?", and "How have treatment side effects affected your life?".

4. Patient oriented rather than symptom oriented approach to treatment of CRPS

I commend the authors for approaching the syndrome of CRPS from another viewpoint that is patient oriented rather than symptom oriented. The healthcare system focuses too much on finding a diagnosis and treating that diagnosis, not the patient. Patients and their needs are forgotten when treatment is only for a diagnosis which may or may not be correct. QualR is a way to refocus the healthcare system more appropriately and put the patient in the spotlight for more compassionate encounters where treatment is difficult and patients suffer without adequate support.

The next step is for Johnston et al. [1] to test their QualR formula and present us with concrete suggestions derived from the study to improve research and patient care for CRPS.

Conflict of interest

The author has no conflict of interest.

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