LETTER TO THE EDITOR



COMMENTARY ON: OUTCOMES OF AMPUTATION DUE TO LONG-STANDING THERAPY-RESISTANT COMPLEX REGIONAL PAIN SYNDROME TYPE I

We read with great interest the paper by Geertzen et al. (1) on amputation outcomes for patients with long-standing therapy-resistant complex regional pain syndrome (CRPS). Their study adds a large number of patients to the published literature in this field. They report important improvements in some of the patients in mobility, pain reduction, and in being able to use a prosthesis. In terms of adverse findings, they found that a subset of patients underwent re-amputation for more proximal spread of CRPS, and that some of the patients had moderate-to-severe phantom pain.

In order to understand what percentage of patients can be considered higher responders to amputation for long-standing CRPS, we would like to propose a set of 5 criteria that would define a high responder. These criteria are:

- Significant reduction in pain.
- Significant improvement in mobility.
- If a prosthesis is fitted, the patient is able to use it.
- There is no re-amputation episode for any proximal recurrence of CRPS.

• There is no phantom pain or less than moderate severity of any phantom pain that may be present. Obviously, only a smaller group of patients will meet all 5 criteria.

We would be grateful if the authors could look at their data and indicate what percentage of the 48 patients meet all of these criteria of high responders.

It may be the case that knowing what such high responder success rates are may be useful for both clinicians and patients who are considering this treatment.

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RESPONSE TO LETTER TO THE EDITOR FROM MARC RUSSO ET AL.

We read the Letter to the Editor by Russo et al regarding our paper (1) with great interest. They propose that patients in our study should fulfil 5 criteria to be labelled as high responders: significant reduction in pain; and significant improvement in mobility; is the patient able to use a prosthesis if fitted; no re-amputation for recurrence of complex regional pain syndrome type I (CRPS-I); and no or less than moderate severity of phantom pain.

The aim of our study was to assess long-term outcomes of amputation in patients with long-standing therapy-resistant CRPS-I regarding mobility, pain, recurrence of CRPS-I, use of a prosthesis, quality of life, and functioning in daily life. Most patients came to our department with the request for an amputation for 1 or 2 specific reasons: to reduce pain, to improve social mobility by removing the affected limb (often called "the obstacle"), to be able to walk again (with a prosthesis), or to get rid of chronic wounds or a limb that was afunctional

and was no longer part of their body scheme. Most participants wanted pain reduction, improvement in social mobility, and did not aim to become a prosthetic walker. The patient's wishes were discussed extensively with them and whether fulfilling their wishes was realistic by means of an amputation. Overall this was patient-focussed care. It would therefore be strange to apply physician-determined criteria to our patients.

Patients were extensively informed about the risks of phantom pain, recurrence of CRPS-I, and other complications. If patients still wanted an amputation they were fully aware of the possible positive and negative effects (deteriorations). Despite reported deteriorations, 98% of the participants reported that they would choose an amputation again if they were in the same circumstances.

In order to provide the results requested by Russo et al., however, we performed *post hoc* analyses. We interpreted their criterion "significant" reduction in

pain and "significant" improvement in mobility as a patient-reported "important" improvement. Indeed none of the patients fulfilled criteria for high responders. Looking at specific aims, all patients aimed for pain reduction and 35 (73%) reported an important reduction in pain. Of the patients who aimed for an improvement in mobility (n=26), 21(81%) reported important improvement in mobility and 14 (54%) reported prosthesis use of 4 h per day or more. Of the patients who aimed at walking with a prosthesis (n=5) only 2 reported prosthesis use of 4 h per day or more. These findings illustrate the difference in what physicians think is important and what patients perceive as important, as has been shown recently (2).

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