



Colleen Johnston PhD Candidate*, Professor Marion Gray*, Dr Florin Oprescu*, Professor Marianne Wallis*

Aim of study

To determine the reactions of health professionals (HPs) to themes uncovered during 17 interviews with people from 5 countries who have been diagnosed with CRPS regarding their lived experience with the condition.

Method

This study involved conversation style interviews via Skype with four HPs who attended the CRPS2017 conference in Cork and are considered leading world experts on CRPS. Data were analysed using the phenomenological method described by van Manen¹.

Background

CRPS is a difficult condition to live with and patients face unique challenges due to the dysfunction of multiple systems. 17 patient interviews and analysis of open internet sites, revealed that living with CRPS is akin to fighting a battle. Interview themes were discussed with HPs.

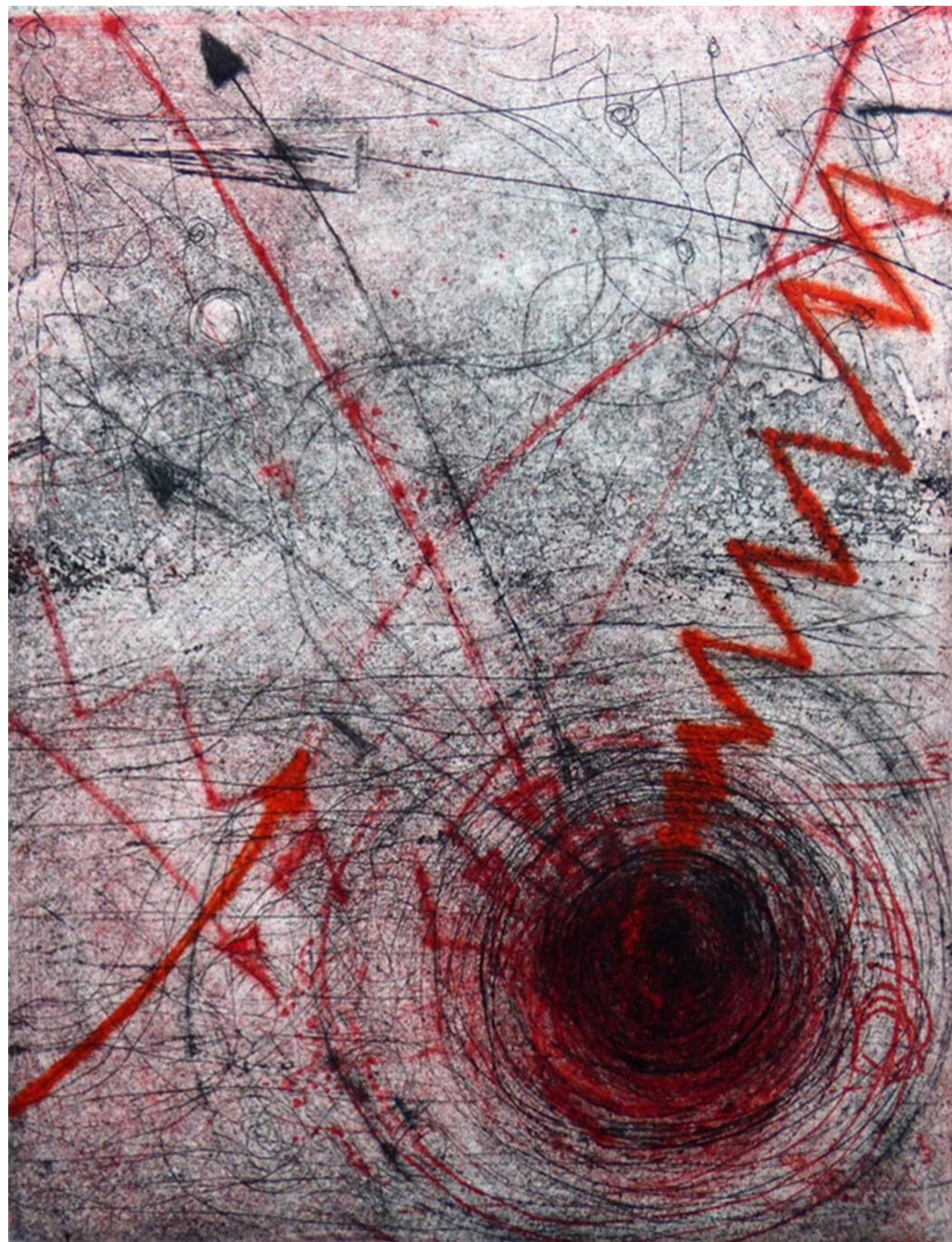


Figure 1. ANGRY by Rosemary Eagle
<http://www.rosemaryeagle.com/art-about-pain.html>

Conclusion

- Better CRPS treatment can result from better understanding the lived experience of patients.
- Adopting a warrior attitude to take power over the condition and activating resilience factors in patients can result in effective pain control and better acceptance and/or adaptation to living with the condition.
- Improving awareness of CRPS in HPs and the general community will improve outcomes and support for patients.

Themes from patient interviews

Dealing with the unknown enemy

- CRPS is a difficult condition to diagnose and treat and few health professionals are familiar with CRPS.
- It is even less known in the general public which affects the level of support available to patients.
- Online patient support groups publicise the McGill Pain Scale defining CRPS as the most painful condition known, yet many are disbelieved about their pain levels.
- Many sufferers have poor health literacy and cannot discriminate between good and unhelpful information sources.

Building an armoury against a moving target

- Patients often experience difficulty accessing knowledgeable HPs.
- Patients often have a fear of spread – especially to internal organs. HPs debate true spread internally as it does not correlate with the Budapest Criteria for diagnosis.
- A balance must be found between non-pharmacologic approaches, medication, side effects and quality of life.
- Patients often consider extremes to find relief, and often trust peers over their HPs.

Battles within the war

- Psychological support can assist in patients accepting their condition.
- Moving the painful body part Vs causing a flare
- Judgement of others such as disbelief of pain or unhelpful comments from HPs.

Developing battle plans with allies

- Patients must often advocate for better treatment.
- Multidisciplinary health care teams offer much to the patient.
- The health practitioner does not always understand the lived experience of the patient and does not partner with them on the health journey.

Warrior or Prisoner of War?

- Some patients catastrophise the condition and suffer immensely while others develop important coping strategies to “get on with life”
- Accepting the condition is the same as giving up or giving in for some patients.

Implications for practice

- Catastrophising can lead to non-compliance with care and adverse outcomes.
- CRPS is nicknamed the suicide disease within the CRPS patient community and few patients realise that most people can recover or achieve remission.
- Education of HPs is enhanced when patients are included.
- Education of patients is necessary to ensure they are accessing appropriate resource material.

Health practitioner responses

“Yeah it definitely is an unknown enemy because not even the people who are providing CRPS care really understand firmly what causes it”.
HP1

“McGill Pain Scale? I think it’s a sign of distress when they do that”.
HP4

“People who are flexible thinkers do better because they are open to thinking of the possibility where things do not have to stay exactly the same”
HP3

“Saying spread is not possible can create conflict within the caring relationship that probably isn’t going to be productive and it probably isn’t going to change the overall management for that person”.
HP2

“I think the next best thing... is multidisciplinary pain treatment where you include the psychological pain management component. Like changing patients who are worriers into warriors”.
HP1

“To understand that it really is a disproportionate response and it is not about them. It is not psychologically or emotionally that they are oversensitive, but that their nervous system has changed”.
HP2

“It must be a comprehensive, large, experienced program, ideally for these patients. We need to have some sort of referral program whereby these long term patients are seen by just a few centres nationally....they really deserve that expertise”.
HP4

“This is very much about a relationship and patient’s choice. Clinicians give information and then it’s up to the patients to choose what they wish to do with it”.
HP3

“As Health care professionals our duty is to produce the results of our research into patient accessible information and to make that widely available...There aren’t that many internet sites of CRPS that do have reputable and useful information”.
HP3