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Current practice in the rehabilitation of complex regional pain syndrome: a survey of practitioners

Caroline Miller^a , Mark Williams^b, Peter Heine^c, Esther Williamson^c and Neil O'connell^d

^aPhysiotherapy Department, University hospitals Birmingham Foundation Trust, Birmingham, United Kingdom; ^bDepartment of Sport, Health Sciences and Social work, Oxford Brookes University, Oxford, United Kingdom; ^cNuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, University of Oxford, Oxford, United Kingdom; ^dDepartment of Clinical Sciences, Brunel University, London, United Kingdom

ABSTRACT

Introduction: International clinical guidelines for Complex Regional Pain Syndrome recommend a wide range and variation of rehabilitation therapies as the core treatment. It is likely that most therapists employ a range of approaches when managing people with Complex Regional Pain Syndrome but a recent Cochrane review identified little evidence relating to the effectiveness of multi-modal rehabilitation. There is need for up to date trials of rehabilitation for Complex Regional Pain Syndrome, but in order to develop a clear model of best practice that can be rigorously evaluated we need to understand current practice.

Method: An electronic survey was disseminated internationally to clinicians involved in the rehabilitation of individuals with Complex Regional Pain Syndrome. The survey aimed to establish which criteria are used for diagnosis and which modalities clinicians use to treat Complex Regional Pain Syndrome and which they consider ineffective or harmful.

Results: 132 valid responses were received. A third of participants did not use any established criteria to diagnose Complex Regional Pain Syndrome. Current practice commonly included patient education, encouragement of self-management, and physical exercises. Cortically directed treatments such as graded motor imagery and psychological approaches were often incorporated into treatment whereas pain provocative therapies, splinting, contrast bathing, and cold and heat therapy were rarely used in the acute or chronic phase of Complex Regional Pain Syndrome.

Conclusion: A broad range of modalities are currently used in Complex Regional Pain Syndrome rehabilitation. Practice appears to be characterized by educational and exercise based interventions delivered in a pain-contingent manner which largely echoes recommendations in international clinical guidelines.

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KEYWORDS

CRPS; therapy; guidelines; questionnaire; treatments; international

► IMPLICATIONS FOR REHABILITATION:

- Patients with Complex Regional Pain Syndrome suffer from a painful and disabling condition for which we still do not know the best treatment options.
- From our survey sample most clinicians use treatments recommended in the international guidelines.
- A large proportion of clinicians from our survey sample are not using internationally recognized diagnostic criteria and we therefore recommend that clinicians become familiar with these criteria and use them for all suspected Complex Regional Pain Syndrome cases.

Introduction

Complex regional pain syndrome (CRPS) is an umbrella term for a variety of clinical presentations characterized by chronic and disabling persistent pain that is disproportionate to any preceding injury and that is not restricted anatomically to the distribution of a specific peripheral nerve. Symptoms typically start in the injured limb but can spread to wider body regions and, as well as pain, may include swelling, discoloration, abnormal hair or nail growth and dystonia [1–3]. While robust data are scarce, CRPS has an estimated incidence rate of between 5.4 and 26.2 per 100,000 person years [4,5]. It frequently affects patients following wrist fracture, developing in 3.8% of those injured [6]. The cause of CRPS is not known, but current consensus suggests it involves an aberrant

inflammatory response with autonomic and central nervous system dysfunction [7]. The impact on sufferers can be severe. People with CRPS are frequently unable to use their affected limbs and their ability to work or participate in social activities is severely restricted, resulting in substantial deterioration of quality of life and high rates of comorbid depression.

CRPS is subdivided into type I and type II based on the absence or presence, respectively, of clinical signs of identifiable peripheral nerve injury. Despite this distinction, core features are common across both subtypes.

CRPS is notoriously difficult to manage and the UK Registry data suggest that patients with CRPS are faced with inconsistent pathways of care, with multiple consultations and often poor

outcomes [8]. International clinical guidelines for CRPS have been published in the last five years from the United Kingdom, the Netherlands and the United States of America (USA) [9–11]. These guidelines are variably informed by published evidence and the opinions of groups of clinical experts and interest groups, with all of them recommending rehabilitation therapies as the core treatment for CRPS. Within this, a broad range of possible treatment modalities are suggested, with some variation in this content across guidelines.

Despite these recommendations, a recent Cochrane review of physiotherapy interventions for CRPS [12] identified an evidence base dominated by small trials of single modality interventions with only one trial of multimodal physiotherapy [13]. This review concluded that there was no compelling evidence of the effectiveness, or lack thereof, of therapy interventions, or to inform an optimal approach to therapy. The relative rarity of CRPS has presented substantial challenges to the conduct of clinical trials of adequate size. In an overview of reviews of all interventions for CRPS, O’Connell et al. [14] found very few large trials for any intervention. Smart et al. [12] suggested that, since it is unlikely that it will be possible to generate sufficient evidence to evaluate the many individual modalities currently applied to people with CRPS, there is a case for taking a pragmatic approach by developing contemporary multimodal, individually tailored “best practice” models of care and prioritizing trials of these programs against usual or minimal care. This would provide pragmatic estimates of effectiveness, which best reflect the value of guideline recommended practice.

With the ultimate aim of developing a “best practice” model of rehabilitation intervention in CRPS which can then be evaluated in a clinical trial, we wanted to identify current practice among clinicians who deliver rehabilitation-based therapy to patients with CRPS. This study aimed to establish how a diagnosis of CRPS was made, which modalities included in recent clinical guidelines clinicians use to treat CRPS, and which modalities they consider unhelpful or harmful.

Methods

This project was approved by the Research Ethics Committee of the Department of Clinical Sciences at Brunel University London.

The project consisted of an online survey of rehabilitation clinicians. The survey comprised a mixture of fixed-response and free-text answers. For a full copy of the survey questions see [supplementary information](#). Individual questions were developed by a team comprised of physiotherapists and clinical researchers.

Fixed response questions included how participants found out about the survey, their professional background, how many years they had been qualified, how many years’ experience they had treating CRPS, the country in which they practice and the clinical setting. Respondents were asked which diagnostic criteria they used (if any), in which body regions they commonly saw CRPS clinically, the number of new and follow-up CRPS patients (acute and chronic) they see in an average month, how many treatment sessions they provided on average and how long they kept them as part of their caseload. No distinction was made in the survey between the subtypes of CRPS-I and II.

Respondents were asked to rate how commonly they utilized a range of treatment options when treating people with acute or chronic CRPS on a 5-point Likert scale (Always, Frequently, Occasionally, Rarely, Never). Open text questions asked respondents, separately for acute and chronic CRPS, to state if they considered any of those treatment options ineffective or harmful and to give reasons for this.

Respondents were asked (closed response “Yes/No”) whether they would be interested in further involvement in research to

develop a best practice model for CRPS rehabilitation. In relation to this, they were asked whether they would be happy for their patients with CRPS to be involved in a clinical trial that randomized them to either a therapy intervention or watchful waiting (minimal care). They were then asked to give reasons for their answer if they responded “no” to that question (open text responses). The survey was hosted on the Bristol Online Surveys software platform and all responses were anonymous.

Survey distribution

We aimed to target rehabilitation therapists (Physiotherapists and Occupational Therapists) and Specialist Nurses with experience of working with patients with CRPS. The survey was publicized by a specific blog post and a banner including a hyperlink to the survey on the international pain science website Body in Mind (www.bodyinmind.org), of which one of the authors (NOC) is the senior commissioning editor. We contacted the administrators of the following UK-based special interest groups: British Association of Hand Therapists, Association of Chartered Physiotherapists in Orthopaedic Medicine and the Physiotherapy Pain Association who emailed an invitation to take part in the survey, which included a link to the survey webpage. Of those, the Physiotherapy Pain Association and the Association of Chartered Physiotherapists in Orthopaedic Medicine sent out a reminder email two weeks after the first email. The survey was promoted on the discussion forum of the UK Chartered Society of Physiotherapy in the “hand therapy”, “pain management” and “rheumatology” forums with links to the survey. In addition, the survey was further promoted through tweets from the twitter accounts of one of the authors (NOC), the Centre for Rehabilitation Research in Oxford and Body in Mind. The survey was open for a two-month period between the dates 1 September 15 to 1 November 15.

Data analysis

Data were analyzed using the Bristol Online Surveys software, Microsoft Excel and SPSS (version 20; IBM, New York, NY). Quantitative data were analyzed using descriptive statistics. This included summarizing the demographic characteristics of the respondents, the frequency of responses to dichotomized questions and the distribution of responses for questions that included Likert style response scales. We conducted a thematic analysis of free text answers which were then summarized with illustrative quotes.

Results

Sample characteristics

A total of 132 surveys were completed. Given the multiple routes to dissemination of the survey, it was not possible to estimate the response rate. Sixty-nine percent (91/132) of respondents were physiotherapists, 26% (34/132) occupational therapists and one participant was a specialist nurse. Six (5%) participants did not respond to this question. Data on geographical distribution of respondents, recruitment sources, respondent experience, clinical settings, diagnostic criteria used and anatomical area treated are all presented in [Table 1](#).

The majority (58%) of respondents were based in the United Kingdom, followed by Australia (12%), New Zealand (5%), Canada (5%), the Republic of Ireland (4%) and single respondents from a range of other nations. No clear differences were observed in the

number of years of clinical experience managing CRPS between those geographical locations, though for many groups the number of respondents was very low. Thirty-four percent (31/91) of Physiotherapists and 35% (12/34) of Occupational Therapists responding to the questionnaire used no formalized diagnostic criteria. With regards to geographical location, 30% (23/77) of respondents from Britain, 56% from Australia (9/16), and 29% (2/7) from New Zealand did not use formalized diagnostic criteria.

The number of new and follow-up acute and chronic CRPS patients seen on average per month was low (Table 2). Using free text responses, the variability on how many sessions of treatment an individual with acute CRPS might receive was wide (from 0 to

unlimited) and how long they were kept on a clinician's caseload ranged from weeks, past a year to as long as it takes to recover. Similarly, with chronic CRPS the number of sessions ranged from 3 days to a 4 week residential to as much as needed. Respondents reported that individuals with chronic CRPS may remain a part of a clinician's caseload for a year or more.

Frequency of treatment modalities used in acute and chronic CRPS

Educational interventions, particularly general education and support, facilitation of self management and pain neuroscience education were very commonly used in the management of CRPS through its acute and chronic phases. However, vocational training and sleep hygiene were used less often (Table 3).

Physical exercise interventions were commonly used in the management of acute and chronic CRPS with functional activity practice and range of motion exercises being the most utilized (Table 4).

Treatments aimed at brain/perceptual training (e.g., mirror therapy, graded motor imagery and mental visualization) were commonly used in patients with chronic CRPS. Cognitive behavioral therapy, acceptance and commitment therapy, mindfulness and interdisciplinary pain management programs were also regularly used with patients with chronic CRPS (Table 5).

With respect to exposure therapies, the greatest number of respondents used tactile desensitization "always" or "frequently". Responses were more evenly distributed for thermal desensitization, stress loading and contrast bathing techniques. Half of

Table 1. Respondent characteristics.

Respondent characteristics	Number of participants (%)
Recruitment source	
Body in mind	37 (28)
British association of hand therapists	31 (23)
Twitter	15 (11)
Chartered Society of Physiotherapy (hand therapy, musculoskeletal, pain management, orthopaedics and rheumatology)	15 (11)
Physiotherapy pain association	11 (8)
Association of chartered physiotherapists in orthopaedic medicine	3 (2)
Other	11 (8)
Missing	9 (7)
Geographical location	
Britain	77 (58)
Australia	16 (12)
New Zealand	7 (5)
Canada	7 (5)
Ireland	5(4)
Other °	17(13)
Missing	3 (2)
Clinical settings*	
Primary care – outpatients	20 (14)
Secondary care – hand therapy clinic	39 (27)
Secondary care – trauma and orthopaedics clinic	8 (6)
Secondary care – rheumatology clinic	5 (4)
Secondary care – pain management clinic	37 (26)
Tertiary care	12 (8)
Other	22 (15)
Diagnostic criteria used*	
Budapest	76 (57)
IASP Orlando criteria	11 (8)
Aitkens and Veldmen	1 (1)
Other	3 (2)
No formalized diagnostic criteria	43 (32)
Experience managing CRPS	
Years	
Mean (SD)	19 (9.5)
Areas commonly affected in patients they treat*	
Areas	
Isolated to upper limb	78 (48)
Isolated to lower Limb	36 (22)
Widespread	3 (1)
All of the above	45 (28)

°The Netherlands: $n=3$ (2%); USA: $n=3$ (2%); Brazil: $n=2$ (2%); Denmark: $n=2$ (2%); 1(1%) respondent from each of the following countries: Italy, South Africa, United Arab Emirates, Switzerland, Germany, Finland and Israel.

*Some respondents provided more than one answer.

Table 2. Number of CRPS patients seen.

	Acute		Chronic	
	Monthly new patients ($n=130$)	Monthly follow-ups ($n=129$)	Monthly new patients ($n=126$)	Monthly follow-ups ($n=120$)
Mean(SD*)	1.02 (1.27)	1.72 (2.23)	1.67 (1.43)	2.60 (2.75)
Median(IQR*)	1.00 (1.5)	1.00 (2.5)	1.00 (1.37)	2.00 (2.00)
Range	0–10	0–15	0–6	0–20

n = number of responses.

*IQR: interquartile range; SD: standard deviation.

Table 3. Frequency of use: educational interventions.

Frequency of use	Acute n (%)	Chronic n (%)
General patient education and support		
Always/frequently	100 (76%)	111 (84%)
Occasionally	5 (4%)	5 (4%)
Rarely/Never	1 (1%)	1 (1%)
Missing	26 (20%)	15 (11%)
Facilitation of self-management		
Always/Frequently	96 (73%)	114 (86%)
Occasionally	5 (4%)	3 (2%)
Rarely/Never	6 (5%)	2 (2%)
Missing	25 (19%)	14 (11%)
Pain neuroscience education		
Always/Frequently	101 (77%)	108 (82%)
Occasionally	2 (2%)	7 (5%)
Rarely/never	4 (3%)	3 (2%)
Missing	25 (19%)	14 (11%)
Vocational support		
Always/frequently	45 (34%)	63 (48%)
Occasionally	31 (23%)	29 (22%)
Rarely/never	9 (7%)	3 (2%)
Missing	34 (26%)	18 (14%)
Sleep hygiene		
Always/frequently	41 (31%)	59 (45%)
Occasionally	26 (20%)	26 (20%)
Rarely/never	37 (28%)	30 (23%)
Missing	28 (21%)	17 (13%)

Table 4. Frequency of use: physical exercise interventions.

Frequency of use	Acute n (%)	Chronic n (%)
Range of movement		
Always/frequently	94 (71%)	95 (72%)
Occasionally	7 (5%)	17 (13%)
Rarely/never	4 (3%)	7 (5%)
Missing	27 (20%)	13 (10%)
Strength exercises		
Always/frequently	49 (37%)	66 (50%)
Occasionally	33 (25%)	26 (20%)
Rarely/never	19 (14%)	24 (18%)
Missing	31 (23%)	16 (12%)
Proprioception exercises		
Always/frequently	59 (45%)	77 (58%)
Occasionally	30 (23%)	27 (20%)
Rarely/never	11 (8%)	9 (7%)
Missing	32 (24%)	19 (14%)
Functional activity practice		
Always/frequently	94 (71%)	109 (83%)
Occasionally	7 (5%)	8 (6%)
Rarely/never	4 (3%)	3 (2%)
Missing	27 (20%)	12 (9%)
Postural exercises		
Always/frequently	43 (33%)	63 (48%)
Occasionally	24 (18%)	18 (14%)
Rarely/never	34 (26%)	32 (24%)
Missing	31 (23%)	19 (14%)
Hydrotherapy		
Always/frequently	18 (14%)	25 (19%)
Occasionally	21 (16%)	21 (16%)
Rarely/never	61 (46%)	66 (50%)
Missing	32 (24%)	20 (15%)

respondents used pain exposure therapy “rarely” or “never” in management of acute or chronic CRPS (Table 6).

Passive therapies, such as thermal therapies, and transcutaneous electrical nerve stimulation were generally used “rarely” or “never”, with responses for splinting, massage and elevation more evenly spread across the response categories (Table 7).

Ineffective/unsafe CRPS treatments

In an optional open text question, participants were asked their views on treatments they felt were ineffective and/or unsafe in the management of acute and chronic CRPS. Forty four participants identified ineffective/unsafe treatments in acute CRPS and 37 identified treatments in the management of chronic CRPS. Of these, 31 and 25 respondents provided their opinions as to why they felt these treatments were ineffective/unsafe in the management of acute and chronic CRPS respectively (Table 8). Views were similar for treatments used during the acute and chronic phases of CRPS.

Respondents felt that splinting could contribute to further disuse, reinforce avoidance of activity and enhance the need to protect the limb within acute CRPS. However, when treating patients with chronic CRPS, it was suggested that it may have a temporary role to improve function.

Concerns were also raised over the impact of cold on existing symptoms in patients with acute CRPS who already experience cold hyperalgesia or problems with their circulation. Respondents thought cold therapy would exacerbate these problems further.

Within both acute and chronic CRPS, respondents commented that pain provocative or aggressive therapy could potentially aggravate symptoms, result in flare ups and negatively affect recovery. Passive therapies such as transcutaneous electrical nerve stimulation and massage were sometimes described as being ineffective in the treatment of both acute and chronic CRPS. These

Table 5. Frequency of use: psychological/brain interventions.

Frequency of use	Acute n (%)	Chronic n (%)
Mirror therapy		
Always/frequently	69 (52%)	82 (62%)
Occasionally	20 (15%)	18 (14%)
Rarely/never	16 (12%)	19 (14%)
Missing	27 (20%)	13 (10%)
Graded motor imagery		
Always/frequently	69 (52%)	87 (66%)
Occasionally	18 (14%)	15 (11%)
Rarely/never	18 (14%)	17 (13%)
Missing	27 (20%)	13 (10%)
Relaxation techniques		
Always/frequently	60 (45%)	76 (58%)
Occasionally	28 (21%)	26 (20%)
Rarely/never	17 (13%)	16 (12%)
Missing	27 (20%)	14 (11%)
Tactile discrimination		
Always/frequently	51 (39%)	59 (45%)
Occasionally	23 (17%)	27 (20%)
Rarely/never	27 (20%)	30 (23%)
Missing	31 (23%)	16 (12%)
Mental visualization		
Always/frequently	59 (45%)	75 (57%)
Occasionally	25 (19%)	25 (19%)
Rarely/never	18 (14%)	14 (11%)
Missing	30 (23%)	18 (14%)
Cognitive behavioral therapy techniques		
Always/frequently	51 (39%)	67 (51%)
Occasionally	23 (17%)	19 (14%)
Rarely/never	29 (22%)	29 (22%)
Missing	29 (22%)	17 (13%)
Acceptance and commitment therapy techniques		
Always/frequently	31 (23%)	53 (40%)
Occasionally	22 (17%)	26 (20%)
Rarely/never	49 (37%)	36 (27%)
Missing	30 (23%)	17 (13%)
Mindfulness techniques		
Always/frequently	36 (27%)	70 (53%)
Occasionally	31 (23%)	14 (11%)
Rarely/never	35 (27%)	30 (23%)
Missing	30 (23%)	18 (14%)
Interdisciplinary pain management program		
Always/frequently	53 (40%)	82 (62%)
Occasionally	22 (17%)	24 (18%)
Rarely/never	27 (20%)	11 (8%)
Missing	30 (23%)	15 (11%)

strategies may contribute to chronicity due to their promotion of dependence on passive strategies.

Particularly, within the rehabilitation of chronic CRPS, respondents raised concerns surrounding the lack of evidence to support mirror therapy in this population and some expressed that it was ineffective from their personal experience. Respondents also raised concerns that aggressive strengthening and passive range of movement may provoke symptoms. Finally, one individual felt strongly that only qualified mental health providers should deliver cognitive behavioral therapy.

Future research

Eighty-four percent (111/132) of respondents expressed an interest in taking part in future research into CRPS. However, the majority (71/132, 54%) of participants responded that they would not be happy for their patients to be randomized to a minimal care (watchful waiting) arm.

Sixty-seven respondents justified their negative replies with an open text response. Three themes were identified from these responses. Firstly, many respondents reported a strong belief in the effectiveness of the treatments and interventions which they were providing at present.

Table 6. Frequency of use: exposure-based therapies.

Frequency of use	Acute <i>n</i> (%)	Chronic <i>n</i> (%)
Tactile desensitization techniques		
Always/frequently	88 (67%)	91 (69%)
Occasionally	10 (8%)	18 (14%)
Rarely/never	6 (5%)	8 (6%)
Missing	28 (21%)	15 (11%)
Thermal desensitization techniques		
Always/frequently	39 (30%)	39 (30%)
Occasionally	26 (20%)	33 (25%)
Rarely/never	37 (28%)	44 (33%)
Missing	30 (23%)	16 (12%)
Contrast baths		
Always/frequently	20 (15%)	11 (8%)
Occasionally	21 (16%)	24 (18%)
Rarely	59 (45%)	78 (59%)
Missing	32 (24%)	19 (14%)
Pain exposure therapy		
Always/frequently	16 (12%)	24 (18%)
Occasionally	11 (8%)	22 (17%)
Rarely/never	66 (50%)	65 (49%)
Missing	39 (30%)	21 (15%)
Stress loading		
Always/frequently	33 (25%)	42 (32%)
Occasionally	30 (23%)	25 (19%)
Rarely/never	36 (27%)	47 (36%)
Missing	33 (25%)	18 (14%)

Table 7. Frequency of use: passive therapies.

Frequency of use	Acute <i>n</i> (%)	Chronic <i>n</i> (%)
Heat therapy		
Always/frequently	18 (14%)	20 (15%)
Occasionally	20 (15%)	27 (20%)
Rarely/never	60 (45%)	66 (50%)
Missing	34 (26%)	19 (14%)
Cold therapy		
Always	12 (9%)	8 (6%)
Occasionally	16 (12%)	27 (20%)
Rarely/never	69 (52%)	77 (58%)
Missing	35 (27%)	20 (15%)
Transcutaneous electrical nerve stimulation		
Always/frequently	10 (8%)	18 (14%)
Occasionally	23 (17%)	23 (17%)
Rarely	65 (49%)	72 (55%)
Missing	34 (26%)	19 (14%)
Splinting		
Always	23 (17%)	20 (15%)
Occasionally	26 (20%)	30 (23%)
Rarely/never	51 (39%)	64 (48%)
Missing	32 (24%)	18 (14%)
Massage		
Always/frequently	32 (24%)	31 (23%)
Occasionally	25 (19%)	27 (20%)
Rarely/never	45 (34%)	59 (45%)
Missing	30 (23%)	15 (11%)
Elevation		
Always/frequently	27 (20%)	15 (11%)
Occasionally	33 (25%)	26 (20%)
Rarely/never	39 (30%)	69 (52%)
Missing	33 (25%)	22 (17%)

I know that with active intensive Occupational Therapy and Physiotherapy rehab I can transform these patients. I would not be able to deny these patients the opportunity for recovery and restoration of function. We have a policy in our team that these patients do not go on a waiting list and are always offered intensive rehab as a matter of urgency.

Secondly, multiple respondents raised ethical concerns, either for themselves or their employers, related to withholding treatment from individuals with CRPS and suggested that it would be "unethical". Other ethical reasons were given on the basis of co-existing psychological distress, which would make it unacceptable

for clinicians to consider entering patients into a trial with a "minimal care" arm.

I believe the key to successful management of CRPS is early intervention; I don't consider it would be ethical to watch and wait.

Finally, individuals had pragmatic concerns, which included not having enough referrals of individuals with CRPS, the concern that patients may have already experienced long waiting lists and the specific challenge delivering minimal care in private practice.

Discussion

This survey of current practice among Physiotherapists, Occupational Therapists and Nurses suggests that rehabilitation in individuals with CRPS is commonly multimodal. The results illustrate current practice in rehabilitation for patients with CRPS and give some indications of which therapies are valued by practitioners and which appear to be less commonly used. This survey was the planned first step in trying to develop a best practice model of rehabilitation that could be tested in randomized controlled trials.

Though many of the respondents used various specific diagnostic criteria, over one third of respondents did not use any. This is at odds with all three recent clinical guidelines [9–11] which all recommend that, given the substantial difficulty in diagnosis, clinicians adopt the Budapest clinical criteria [15] for diagnosing CRPS. Failure to use these criteria raises the risk that some of the clinical cases upon which some respondents based their responses were not clearly cases of CRPS.

The American, UK and more recent Dutch guidelines [9–11] recommend physical rehabilitation for patients with CRPS. The UK guidelines [10] specifically recommend education also as one of the pillars of treatment. Within this survey, educational approaches and physical exercises were the most frequently used treatment modalities; tactical desensitization, cortically directed rehabilitation techniques and relaxation were also used, but passive and pain provocative therapies appear to be less popular.

The duration and intensity of treatment varied significantly across the respondents. Whilst the median number of patients with CRPS seen in a month is quite low these patients often appear to continue receiving treatment by clinicians for many weeks or months and at times longer than a year. Within the international guidelines, there is no recommendation for length of treatment [9–11].

Our survey found that passive therapy, which included splinting, heat and cold therapy, transcutaneous electrical nerve stimulation and massage, was rarely used by respondents in the management of CRPS and passive treatments were often criticized in the free text replies. This is consistent with clinical guidance from the USA, United Kingdom and the Netherlands which places an emphasis on progressive active intervention [9,10,11].

Mirror therapy and graded motor imagery were less frequently used by participants than educational and physical activity interventions despite being recommended by the American guidelines [9]. Some free text responses alluded to a growing uncertainty among some clinicians around the effectiveness of mirror therapy and graded motor imagery, particularly with chronic CRPS. In the chronic pain literature, there are conflicting reports of the effectiveness of motor imagery or left and right judgment training when used as stand-alone treatments [16] and a recent Cochrane review identified that the evidence base for graded motor imagery from clinical trials, while suggesting positive benefits, is limited [12].

There was a general reluctance from respondents to engage individuals with acute or chronic CRPS in pain exposure therapy.

Table 8. Free text answers to ineffective/unsafe CRPS treatments.

Treatments (<i>n</i> – number of respondents providing free text acute/chronic)	Example quotes
Splinting (<i>n</i> = 11/8)	“Splinting. It is likely to only reinforce behaviors of protecting the affected limb and can be seen as treating it “differently” to any other body part rather than allowing an experience where the person can begin to view their limb as part of them again.” (acute) “... splinting is very unlikely to be helpful but if it facilitates function temporarily I wouldn't rule it out ...” (chronic)
Hot/cold strategies (<i>n</i> = 12/10)	“Never cold therapy as most of my patients have extreme cold hyperalgesia” (acute) “With the changing circulatory issues the patients have it is difficult to use thermal therapies unless the patient has a good understanding” (acute)
Pain exposure (<i>n</i> = 10/6)	“Pain exposure in the acute stage to be avoided, aggravates symptoms” (acute) “... pain exposure therapy, doesn't sound a good idea if it leads to flare up and sustained cortical activation consistent with high pain levels” (chronic)
Passive strategies (massage, elevation, acupuncture, transcutaneous electrical nerve stimulation) (<i>n</i> = 15/15)	“massage and passive strategies can allow the patient to have a false narrative for their condition which may be a factor in its perpetuation” (acute)
Graded motor imagery and mirror therapy (<i>n</i> = 4/4)	“Mirror therapy & graded motor imagery despite all the hype doesn't seem to do much even in those that have laterality problems.” (chronic)
Aggressive strengthening and passive range of motion (<i>n</i> = 9/9)	“giving strengthening exercises, which may flare up the pain” (chronic)
Cognitive behavioral therapy/Acceptance and commitment therapy (<i>n</i> = 1/1)	“Acceptance and commitment therapies and cognitive behavioral therapies are dangerous in the hands of non-psychologists/mental health providers - practicing in alignment with cognitive behavioral therapy and acceptance and commitment therapy principles is fine, but not delivering these therapies” (acute)
Hydrotherapy (<i>n</i> = 0/2)	“Hydrotherapy – I don't believe it is useful for very many things” (chronic)

This is also evident in the free text section of the survey and reasoning provided included concerns regarding flaring up existing symptoms. The Dutch guidelines [11] recommend that treatment is provided in a pain contingent manner initially and may progress to time-contingent. The US guidelines [9] also recommend progression of treatment in a pain contingent manner, although they do suggest that there may be a role for time-contingent/pain exposure therapy. The UK guidelines [10] do not specify whether treatment should be pain or time contingent.

However, pain-related fear has been shown to be related to increased CRPS 1 disability [17] and early case series work evaluating pain exposure therapy observed improvements in pain and disability [18,19]. Evidence from recent trials relating to pain exposure approaches for CRPS has been conflicting. Barnhoom et al. [20] compared a pain exposure-based therapy to pain contingent rehabilitation based on the Dutch guidelines in 56 people with CRPS 1. On intention to treat analysis, there were no significant differences in combined pain, active range of movement and temperature scores between the pain exposure group and the usual treatment group, though the trial was impacted by substantial drop-out, particularly from the conventional treatment arm. A more intensive cognitive behavioral graded exposure-based approach was compared to a pain contingent “treatment as usual” arm in another study in 46 people with CRPS 1 [21]. In this trial, exposure therapy was more effective than treatment as usual, delivering clinically important improvements in self-reported disability and pain in CRPS 1. A recent commentary on that trial [22] raised some concern that the “treatment as usual” arm appeared to be somewhat obsolete with a focus on the goal of pain extinction rather than improvement in function, and the inclusion of passive therapies such as transcutaneous electrical nerve stimulation and massage. It is likely in light of our results that this control may not reflect “treatment as usual” among the respondents of this survey and it has been suggested that this potentially sub-optimal control comparison may have contributed to positive findings in favor of exposure therapy in this trial [22].

Limitations

While we have been able to gain responses from a number of therapists of different professional backgrounds and who practice

in different countries and clinical environments, any survey of this type is at risk of response bias. The dominance of the Body in Mind website and certain professional special interest groups as the recruiting gateway to the survey clearly suggests that the results may over-represent the views of those groups and countries where they are based (i.e. the UK and Australia). It may not represent the views of those practicing in countries not represented here (e.g., the USA) or indeed more generalist clinicians who may not have such a clear focus on chronic pain management or hand therapy or a special interest in the treatment of CRPS. The low numbers of participants in most geographical location groups has limited the scope for meaningful analysis of practice differences across locations. Due to the online approach to recruitment and the strategy of maximizing the reach of the survey through social media, it is not possible to conduct any meaningful analysis of response rates or patterns.

Due to the survey design, respondents were not obliged to complete all questions resulting in a sizeable proportion of missing data regarding the type of treatment modalities used. This was particularly evident for questions related to acute rather than chronic care (19–30% missing responses compared to 10–17%, respectively). We are not sure why this occurred, nor why there were fewer responses for acute versus chronic care.

A team of physiotherapists and researchers developed the survey; however, it was not piloted and has not been formally validated. The survey is exploratory in nature and therefore our analysis is essentially descriptive.

Conclusions and future research

Educational approaches and physical exercises are frequently used treatment modalities within rehabilitation for patients with Complex Regional Pain Syndrome, among our sample of survey respondents. Passive treatments and pain provocative therapies are less valued by respondents to this survey. In our sample, current practice appeared to be broadly consistent with guidelines from the United Kingdom, the Netherlands and the USA. Over one-third of respondents did not use diagnostic criteria.

The next step may be to develop consensus on best practice. Consensus methodology such as a Delphi or Nominal Group Technique could support the design of a complex intervention

which could be evaluated in line with the medical research council guidance on developing complex interventions [23].

A challenge for future research is professional “equipoise”. This survey demonstrated that many therapists would not be happy to randomize patients with CRPS into a minimal care group despite the limited evidence supporting rehabilitation approaches. This raises the question of what type of control might be optimal and feasible in such trials.

Finally, recruitment of adequate numbers of participants to a clinical trial that would meaningfully reduce the uncertainty surrounding the benefits of rehabilitation remains a substantial challenge as the numbers seen at each center are relatively small.

Disclosure statement

The authors report no declarations of interest

ORCID

Caroline Miller  <http://orcid.org/0000-0002-4866-0847>

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