**Title**: Designing and delivering an educational package to meet the needs of primary care health professionals in the diagnosis and management of those with Complex Regional Pain Syndrome.

**Short title**: A primary care educational initiative for CRPS

**Word count**: 2,075

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**Sponsors:** The project was supported financially by Pfizer Ltd and Avon Primary Care Research Collaborative.

**Introduction**

This short report presents the evaluation of the efficacy of a primary care educational intervention aimed at improving the detection, diagnosis and appropriate treatment of patients with Complex Regional Pain Syndrome (CRPS), which affects one in 60 of the UK population during their lifetime (deMos et al. 2007).

**Need for the course**

Complex Regional Pain Syndrome (CRPS) is characterised by excruciating pain of unknown origin in a limb (Stanton-Hicks et al. 1998), which continues well after the injury has healed (Bruehl et al. 2002). Whilst the majority of CRPS cases recover, 15-26% experience on-going and unremitting symptoms causing long term disability (Schasfoort et al. 2004). Chronic pain sufferers (potentially with undiagnosed CRPS) are typically seen in primary care settings by GPs, Physiotherapists and Occupational Therapists. As CRPS is viewed as rare, education about the disease is not considered to be a priority within postgraduate training. Yet, without the appropriate knowledge primary healthcare professionals are unable to identify, accurately diagnose and treat CRPS. Hence these patients are seen repeatedly seeking a cause and treatment for their pain (Chief Medical Officer, 2008) and often inappropriate, ineffective and costly treatment is given as a result (Quisel, 2005).

**Selection of the course attendees**

A course was developed for GPs, and Physiotherapists and Occupational Therapists (termed Allied Health Professionals- AHPs). To recruit the GPs, existing postgraduate meetings in the south-west of England were targeted. One session within the training programme was negotiated with the primary care education network co-ordinators. As a comparable education network did not exist for AHPs, the need for education to be specifically arranged and delivered in suitable primary care settings was recognised. The events were arranged with primary care clinicians who advertised the education via their local email networks. However, one additional ad hoc event became available over the course of the project and we adapted the programme to fit within this.

**Content, format and duration of the course**

Publication of the UK guidelines on the best management of CRPS by the Royal College of Physicians in 2011 (Goebel et al. 2011) provided a perfect framework on which to model a suitable educational intervention. Profession specific sections within the CRPS guidelines were used to develop two different educational packages, recognising the different educational requirements of each group. The education was delivered by an Occupational Therapist and a Consultant Nurse, with CRPS expertise.

The content of the GP focussed educational intervention delivered over an hour included: recognising the signs and symptoms of CRPS and how these may differ from other medical conditions, a written check list to apply the Budapest diagnostic criteria (Harden et al. 2010) and a treatment and referral pathway.

Content for AHPs course concentrated on detecting the signs and symptoms, obtaining a diagnosis and delivering rehabilitation strategies appropriate to the setting. Furthermore, the ability to distinguish differences in disease severity and potential need for referral to other primary care colleagues or CRPS specialist services was included. In addition, the AHP education included hands-on teaching of two rehabilitation strategies, desensitisation (Lewis et al. 2010) and mirror visual feedback (McCabe et al, 2003). A therapist treatment algorithm based on the CRPS guidelines was also presented. Given the additional education material the session time was approximately two and a half hours, longer than the GP session.

In both cases an expert CRPS patient spoke about the condition and their experience of it giving attendees the opportunity to observe signs of CRPS first hand. In addition to the face to face education, a pack of written information was also provided with resources to take away for future reference and to extend learning if required.

*Data collection and analysis*

Prior to each educational session data were acquired via a self-report questionnaire. The questionnaire asked about the number of CRPS patients seen in the previous year, signs and symptoms normally expected in CRPS patients and treatments commenced. In addition, GPs were asked how they normally diagnose CRPS, treatments offered and specialities used in referral.

An evaluation questionnaire was completed by attendees just after the education session to gather learning performance data. This questionnaire contained evaluation questions such as, Were the session aims appropriate? Would you like the session aims changed? Can you identify one new thing you have learnt in the session? In addition, the participants were asked, in the light of the session, how many CRPS patients they may have seen in the previous year and whether they felt they would change their practice as a result of attendance.

The pre- and post-questionnaire evaluation comments provided descriptive data which were managed through an Excel spread sheet to identify trends. Pre and post questionnaire results were matched to allow comparisons of data.

**Outcomes and evaluation**

In total 57 AHPs, the majority physiotherapists, one occupational therapist and one podiatrist, and 22 GPs provided data via the questionnaires.

The GPs and AHPs were able to identify a number of the signs and symptoms of CRPS prior to the educational intervention. GPs mentioned abnormal persistent pain after injury, skin and sensory change, skin discolouration, hypersensitivity, hair loss and oedema. AHPs reported changes in skin colour, temperature and hair and nail growth, increased sweating, swelling, reduced function, hypersensitivity and allodynia, as indicators of CRPS. However, it was clear that issues of altered body image and perception of the affected limb(s) were less well known. GPs suggested CRPS was difficult to diagnose, with specialist opinion being sought in some cases. Difficulties in achieving an accurate and timely diagnosis for CRPS are evidenced elsewhere (Jänig and Baron, 2003; Quisel, 2005; Allen et al. 1999).

A range of treatments were used, the most common being mirror therapy. Patients were most frequently referred to pain clinics (n=33) (58%), specialist centres (n=7) (12%), rheumatology (n=5) (9%), occupational therapist (n=3) ( 5%) and hand therapists (n=3) ( 5%). A range of treatments were employed for CRPS patients. In addition to onward referral, GPs prescribed a range of anti-depressants and other medication. Following the education session, GPs reported feeling more informed about and more able to diagnose CRPS. When comparing the perceived CRPS incidence figures provided, 12 GPs (55%) had changed their views about the number of CRPS patients they had seen in their practice following the educational intervention.

A total of 19 GPs (36%) suggested they would change their practice after the session. Examples offered included; commencing early mobilisation, asking patients more relevant questions, providing better patient education and being open to ‘strange’ symptoms. The aims of the session were felt to be appropriate and 21 (95%) respondents identified new learning, which included knowledge of the UK Guidance document and the existence of specialist services. Most felt that additional education was not required, though one would have liked more on patient treatments and a further GP mentioned updating on differential diagnosis and medications.

The AHPs were using mirror therapy, desensitisation and exercise therapies most frequently, treatments shown to reduce pain and improve other clinical symptoms, with the additional benefit that once learnt, patients can practice the techniques in the community (McCabe et al.2003; Cacchio et al 2009; Pleger et al. 2005; Lewis et al. 2011).

All but one AHP identified new learning and all felt the aims and content of the session were appropriate. A number of staff identified possible additional learning needs, three felt they would like additional case studies, one wanted increased understanding of treatment and one, more on mechanistic theories of CRPS. Ten mentioned it was useful to have patient input to the session. Seven reported new knowledge of the Budapest diagnostic criteria, four highlighted the use of mirror therapy and a number referred to increased knowledge of specialist services, with better understanding of CRPS overall. This was reflected in the reported perceived number of CRPS patients seen in the previous year, where 18 (82%) staff changed their initial pre-questionnaire figure following the session.

All but three of AHPs (n=54, 95%) reported they would change their practice following the session. This included earlier recognition and referral (n=16), mirror therapy (n=8), desensitisation (n=6), referral to specialist centres (n=6), improved patient education (n=6) and the use of the Budapest Criteria (n=4). One AHP also stated they would educate their staff.

Whilst the educational intervention has had some impact on learning, a very small number of the GPs and AHPs felt this could be enhanced. A couple of staff felt they would like to hear more about treatments, GPs were also interested to hear about medications and differential diagnoses while the AHPs would like more on the theory of CRPS and patient case studies.

The study was limited by the small sample sizes, however, this feasibility study demonstrated that GPs and AHPs were able to learn from the educational intervention and identified ways to apply this knowledge to future practice. Of course, whether *actual* change in practice occurred subsequent to this intervention we cannot verify as the project was not designed to evaluate this. It would be important to evaluate this formally if our educational package were to be implemented into routine clinical education.

**Acknowledgments**

We are grateful to the CRPS patients in the Royal National Hospital for Rheumatic Diseases, Bath for their support in developing data collection tools and patient survey completion. The project was also facilitated by staff of the Severn Deanery.

**References**

Allen G, Galer BS, Schwartz L (1999). Epidemiology of complex regional pain syndrome: a retrospective chart review of 134 patients. Pain 80 (3): 539-44.

DOI 10.1016/S0304-3959(98)00246-2

Bruehl S, Harden RN, Galer BS, Saltz S, Backonja M, Stanton-Hicks M (2002). Complex regional pain syndrome: are there distinct subtypes and sequential stages of the syndrome? Pain 95 (1-2): 119-24. DOI 10.1016/S0304-3959(01)00387-6

Cacchio A, De BE, Necozione S, di OF, Santilli V (2009). Mirror therapy for chronic complex regional pain syndrome type 1 and stroke. New England Journal of Medicine 361 (6):634-6. DOI 10.1056/NEJMc0902799

Chief Medical Officer (2008). Pain: Breaking the barrier. In: Chief Medical Officer 2008 Annual Report. London : Department of Health.

deMos M, de Bruijn AGJ, Huygen FJP, Dieleman JP, Stricker BHC, Sturkenboom MCJM (2007). The incidence of complex regional pain syndrome: A population-based study. Pain 129 (1):12-20. DOI 10.1016/j.pain.2006.09.008

Goebel A, Barker C, Turner-Stokes L (2011). Complex regional pain syndrome concise guideline. Clinical Medicine 11 (6):596-600. ISBN 1470-2118

Harden, R.N., Bruehl, S., Perez, R.S.G.M., Birklein, F., Marinus, J., Maihofner, C., Lubenow, T., Buvanendran, A., Mackey, S., Graciosa, J., Mogilevski, M., Ramsden, C., Chont, M. and Vatine, J.J. (2010) Validation of proposed diagnostic criteria (the “Budapest Criteria”) for Complex Regional Pain Syndrome. Pain. 150 (2), pp.268-274.DOI 10.10162Fj.pain.2010.04.030

Janig, W. and Baron, R. (2003) Complex regional pain syndrome: mystery explained? Lancet Neurology . 2 (11), pp.687-697. DOI 10.1016/S1474-4422(03)00557-X

Lewis J, McCabe C (2010). Body perception disturbance (BPD) in CRPS. Practical Pain Management. 10: 60-6. ISSN 1541-5988

McCabe CS, Haigh RC, Ring EFL, Halligan PW, Wall PD, Blake DR (2003). A controlled pilot study of the utility of mirror visual feedback in the treatment of complex regional pain syndrome (type 1). Rheumatology 42 (1): 97-101.

Pleger, B., Tegenthoff, M., Ragert, P., Forster, A., Dinse, H., Schwenkreis, P., Nicolas, V. and Maier, C. (2005) Sensorimotor returning in complex regional pain syndrome parallels pain reduction. Annals of Neurology. 57 pp.425-429.

Schasfoort FC, Bussmann JB, Stam HJ (2004) Impairments and activity limitations in subjects with chronic upper-limb complex regional pain syndrome type 1. Archieves of Physical Medicine and Rehabilitation. 85 (4):557-66.

Stanton-Hicks M, Baron R, Boas R, Gordh T, Harden RN, Hendler N, et al. Complex regional pain

syndromes: Guidelines for therapy. The Clinical Journal of Pain 1998;14:155-66.

Ref ID: 51

Quisel A (2005). Complex regional pain syndrome underdiagnosed. The Journal of Family Practice. 54 (6):524-32.