



Online social support for Complex Regional Pain Syndrome: A content analysis of support exchanges within a newly launched discussion forum



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ARTICLE INFO

Article history:

Available online 17 May 2015

Keywords:

Complex Regional Pain Syndrome
Online support groups
Patient interaction
Content analysis
Social Support Behavior Code
Optimal Matching Theory

ABSTRACT

Complex Regional Pain Syndrome (CRPS) is a debilitating illness characterised by unexplained pain that is disproportionate to any initiating event. Individuals living with CRPS can become socially isolated, and online support communities may provide them with an increased support network through which they can access support at any time. However, most research into online social support has focussed on established communities rather than newly launched communities, and little is known about online support for CRPS. This study explores the experiences of members in a newly launched CRPS discussion forum, to examine the support content of messages and how support processes become established. Content analysis was used to code messages using the Social Support Behavior Code. Emotional support was the most common, followed by informational, esteem and network support, with tangible aid occurring only rarely. Support processes started almost immediately when the group was launched, similar to what happens in a face-to-face support group where strangers meet for the first time and immediately support one another. The results support Optimal Matching Theory, and indicate that online support may have an important role to play in the CRPS 'four pillars of intervention'.

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1. Introduction

1.1. Complex Regional Pain Syndrome

Complex Regional Pain Syndrome (CRPS) is an unpleasant and debilitating illness characterised by ongoing, unexplained pain that is disproportionate to any initiating event, and accompanied by changes in skin colour or temperature, sweating, or motor dysfunction (Harden, Bruehl, Stanton-Hicks, & Wilson, 2007). Symptoms typically develop following an injury to the affected area but can also arise spontaneously (McCabe & Blake, 2008). It is possible to distinguish between two types of CRPS based upon the absence (type 1) or presence (type 2) of nerve damage (Stanton-Hicks et al., 1995), although disease management is the same for both types.

The incidence rate has been estimated at 26.2 new cases per 100,000 annually (de Mos et al., 2007). Females are four times more likely to be diagnosed with CRPS than males, those aged 50–70 are most at risk of developing the illness, and CRPS is more

likely to affect the upper limbs of the body (de Mos et al., 2007; Sandroni, Benrud-Larson, McClelland, & Low, 2003). The disease has a high resolution rate, with 74% of cases recovering within twelve months of diagnosis (Sandroni et al., 2003). Little is known about factors that predict a poor prognosis. A survey of experts indicated that poorer outcomes may be associated with clinical factors like sensory, motor and autonomic changes, having CRPS on upper body regions, and an illness duration greater than three months, together with non-clinical factors such as the absence of a social network, someone or something causing the problem, and illness-related conflict with an employer (Brunner, Nauer, & Bachmann, 2011).

Little is understood about the underlying causes of the illness, making chronic CRPS a difficult condition to treat (Bruehl, 2010). Treatment requires an interdisciplinary approach using the 'four pillars of intervention' (Turner-Stokes & Goebel, 2011), where the main goal is to help individuals self-manage their condition (Rodham, Boxell, McCabe, Cockburn, & Waller, 2012). Control appears to be particularly important in this process, with individuals needing to learn how to control their CRPS rather than letting the illness control them (Rodham, McCabe, Pilkington, & Regan, 2013). The 'four pillars' focus on education, pain relief, rehabilitation and psychological intervention.

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First, information is provided to educate the individual about their illness and ensure they have the appropriate resources for self-management. This can be done through information leaflets and engaging with healthcare professionals to set goals and discuss appropriate methods of treatment (Turner-Stokes & Goebel, 2011). Information leaflets help the individual to learn more about what CRPS is, what it is like to live with the condition, and outline some of the treatment methods that can be used, while discussions with specialists will help the individual to set appropriate goals, review their progress, and promote insight into how their own behaviour can exacerbate pain levels (Goebel, Barker, & Turner-Stokes, 2012).

Second, pain relief medication and procedures can be considered to control pain levels and help the individual to sleep. Pharmacological interventions use a range of drugs including anaesthetics like ketamine to reduce pain levels, corticosteroids to reduce both pain and inflammation, and anticonvulsants like gabapentin to reduce neuropathic pain, while invasive treatments like spinal cord stimulation can also reduce long-term pain and improve quality of life for some individuals (Cossins et al., 2013; Hord & Oaklander, 2003; Perez et al., 2010). Currently the evidence for pain relief is only preliminary and there are no medications licensed in the UK for treating CRPS, so drugs should only be administered in accordance with specialist guidelines for neuropathic pain (Goebel et al., 2012).

Third, physical and vocational rehabilitation should be used to restore normal functioning in the affected limb. A range of physical rehabilitation techniques can be used including tactile and thermal desensitisation to normalise the sense of touch, mirror therapy to address altered perceptions of the limb, and retraining the body to encourage the individual to adopt a normal posture (Goebel et al., 2012). Vocational rehabilitation can help the individual to stay in employment or return to work, possibly with the aid of governmental support schemes (Goebel et al., 2012), thus avoiding the financial and psychosocial disadvantages of not working (Kemler & Furnée, 2002).

Fourth, psychological interventions can be used to address other factors contributing to pain and disability. Individuals with chronic pain have an increased risk of depression and anxiety (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997; Kroenke et al., 2013), which may require specialist treatment. It can also help the individual to develop coping skills, promote the importance of positive thinking, and identify how family dynamics or other types of counter-productive behaviour could impact on the illness (Goebel et al., 2012; Turner-Stokes & Goebel, 2011).

This study investigates how social support received on the Internet can contribute to the CRPS four pillars of intervention, by looking at online social support in the context of Optimal Matching Theory.

1.2. Optimal Matching Theory

Optimal Matching Theory (Cutrona & Suhr, 1994) proposes that social support is a multidimensional construct where the controllability of a stressful event determines what type of social support is likely to be most effective for that individual. The Social Support Behavior Code (Cutrona & Suhr, 1992) identifies five main categories of social support: informational support (factual information and advice), emotional support (comfort and warmth), esteem support (compliments and reassurance), network support (sense of membership and belonging) and tangible aid (practical help). Optimal Matching Theory divides these social support categories into two groups, action-facilitating support and nurturant support.

Action-facilitating support is important when helping people to cope with controllable problems, and involves providing the stressed individual with informational support and tangible aid.

This could take the form of advice, factual information, teaching them how to do something, or giving practical help and assistance. Action-facilitating support provides the resources needed to help the individual overcome the problem that is causing their distress, and solves or eliminates the cause of their difficulties.

Nurturant support is important for coping with uncontrollable problems, and involves providing emotional and network support. This can take the form of showing the stressed individual that you care, expressing concern for their wellbeing, empathising with their situation, offering to be there, and reminding the sufferer that they are not alone in their experiences. Nurturant support helps the individual to cope with the negative effects of the stressful situation and reduces any negative emotions they may be experiencing, without making any attempt to solve a problem that is beyond their control.

Esteem support can be important in both action-facilitating and nurturant support. Reassuring the stressed individual of their value and competence as a person serves the dual function of encouraging them to actively tackle controllable problems, and reminding them that they are not to blame when faced with uncontrollable situations.

Health problems can be a source of stress that triggers the need for support, particularly if an illness is uncontrollable or negatively impacts upon other aspects of a person's life such as their income or level of contact with others (Turner, Grube, & Meyers, 2001). Several studies investigating online support communities have supported Optimal Matching Theory. For example, Braithwaite, Waldron, and Finn (1999) reported that emotional support was important in online support for disabilities, where sufferers are unable to control their environment or how others perceive them. Eichhorn (2008) found similar levels of both informational and emotional support in an eating disorder online community, where informational support helped sufferers overcome problems while emotional support helped those who felt they had little control over their illness. Similarly, in a study of online support for the families of children with cancer, Coulson and Greenwood (2012) found that informational support helped with controllable issues such as parenting and social activities, while emotional support helped with uncontrollable problems such as those relating to diagnosis and treatment.

1.3. Online social support

Social support may be particularly important for individuals living with CRPS. Perceived social support helps to reduce depression, negative moods and feelings of anger, and can also reduce the level of pain experienced the following day (Feldman, Downey, & Schaffer-Neitz, 1999). Moreover, individuals with CRPS often find themselves becoming socially isolated and withdrawn. CRPS restricts an individual's ability to participate in social and recreational activities (Galer, Henderson, Perander, & Jensen, 2000), and it can leave them with a greatly reduced network through which they can obtain support (Rodham, McCabe, & Blake, 2009). This means that social support received over the Internet may be particularly beneficial to individuals with this debilitating condition.

Online support communities (also known as 'online support groups') are a type of virtual community with a health-related focus. Web forums and other online groups allow members to communicate over the Internet by exchanging messages with like-minded individuals who have the same health condition and have been through similar experiences, in order to support one another and exchange social support, information and advice.

There are several advantages to receiving social support over the Internet, some of which may be particularly important for individuals with CRPS. Online support communities can be accessed at

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