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

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A B S T R A C T

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 addresses 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

any time of the day or night, the anonymity of the Internet makes it easier to discuss sensitive or embarrassing topics, and they can help members to feel less isolated and alone in their experiences (Coulson & Knibb, 2007; Malik & Coulson, 2008a). Individuals who participate in online support communities score significantly higher on several coping strategies and derive a range of benefits from sharing their experiences and exchanging support, empowering them to take a more active role in managing their condition (Mo & Coulson, 2010).

The disadvantages of online social support include reading about the negative experiences of other people, possible exposure to misleading information, having to read large numbers of messages that may not be directly relevant, and a lack of physical proximity to others (Coulson, 2013; Malik & Coulson, 2010). Messages and questions posted to online communities can sometimes go unanswered (Attard & Coulson, 2012; Malik & Coulson, 2010), and concerns about the possibility of receiving aggressive or hostile replies can lead some members to become 'lurkers' who read messages without making any contributions of their own (Preece, Nonnecke, & Andrews, 2004). However, research indicates that most postings are overwhelmingly supportive with few instances of misleading information or inappropriate replies (van Uden-Kraan et al., 2008).

Despite the growing body of research investigating online social support, little is known about how support processes become established when a new online support community is launched. Iriberri and Leroy (2009) studied the lifecycle of online communities and found that they evolve through five distinct stages, comprising inception, creation, growth, maturity and death. The first two stages, inception and creation, involve devising an idea for a new community and developing the software needed to launch it on the Internet. The third stage, growth, occurs when the forum is launched. New members will join the group and start posting messages to build relationships, ask questions, support one another, and enforce community etiquette. By the fourth stage, maturity, the group has become established and trusting relationships will have formed between members. These established communities often produce large volumes of messages, and they have existing group norms and support processes through which members assist one another. They may also have large membership bodies with hundreds or thousands of members, consisting of a mixture of both newly joined individuals and long-standing members. Many long-standing members will know each other closely after spending months or years interacting, supporting one another, and sharing information and advice, while new members simultaneously seek to integrate themselves within the community. The final stage, death, occurs if members lose interest in the group and there is no longer enough activity to sustain discussions.

The growth stage is critically important for how support processes become established, and there are two distinct possibilities for how this might occur. The first possibility is that support could slowly build and develop as new members join, in a similar manner to a snowball effect. A group might begin with a small number of members who tentatively exchange support, with support levels then growing over time as additional members join the group and take part in discussions. Alternatively, high levels of social support could be present from the start, with members joining the group, meeting for the first time and supporting each other straight away, similar to what might happen in face-to-face support groups.

1.4. Rationale for the study

Most studies investigating online social support have focussed on existing communities that have been established for quite some time. For example, researchers have looked at the social support content of messages posted in established online support communities for physical disabilities (Braithwaite et al., 1999), Huntington's disease (Coulson, Buchanan, & Aubeeluck, 2007), childhood cancer (Coulson & Greenwood, 2012) and HIV/AIDS (Coursaris & Liu, 2009; Mo & Coulson, 2008), to examine what kind of social support is present within these communities and how social support is expressed.

Little is known about what happens when a new online support community is launched. We do not know about the provision of social support within a newly created online community or how support processes become established. Furthermore, despite the prevalence of CRPS and the importance of social support for individuals with this debilitating illness, we only know of one published study that has investigated the use of online communities for CRPS (Rodham et al., 2009). This means that little is known about what kind of social support members exchange within these communities, or how this potentially benefits them.

This study is a unique opportunity to explore the experiences of individuals with CRPS in a newly launched discussion forum. The aim is to examine the social support content of messages posted to the forum, to investigate what kind of social support is present and how support processes become established.

2. Methods

2.1. Data collection

The data for this study was obtained as part of a wider investigation into health-related Internet use by people living with chronic CRPS, to study how Internet technology can be used to support the needs of people with this debilitating condition. The project was developed in collaboration with the University of Bath and the University of Nottingham, with a research team that included clinicians, IT experts, academics and patients. Part of the project involved creating and launching a brand new online discussion forum that was used as a dedicated online support community for people living with CRPS.

Many online forums provide open access to their message archives, making it possible for anyone to access the group and read messages. In contrast, this study used a closed forum where access was restricted to members who have joined the study and registered with a username and password. This provided a high level of privacy within the community, creating an environment where members could openly share their feelings and experiences without any possibility of others intruding or being able to view their messages.

The study ran for seven months from 1 June 2012 through to 31 December 2012. During the first month new members registered with the forum, introduced themselves and took part in discussions. Forum activity then continued for a further six months. The forum had 60 registered members including 'lurkers' and administrators.

There were four boards on the forum, each dedicated to discussions about different aspects of CRPS and the wider research project. The 'Raise awareness of CRPS' and 'Is the forum working for you?' boards were researcher-led, while the 'Welcome' and 'Your Thoughts and Experiences' boards were member-led. The two member-led boards were selected for analysis because discussions on these boards reflected the thoughts, feelings, concerns, opinions and experiences of individuals with CRPS, while the other two boards were concerned with administration and communication by the research team. All messages posted on both boards were selected and downloaded for analysis, covering the seven month period up until 31 December 2012. The data consisted of 76 messages (2 threads) from the 'Welcome' board and 145 messages (17 threads) from the 'Your thoughts and experiences' board.

2.2. Participants

Participants were recruited through an announcement sent to the membership bodies of UK charities and organisations that represent individuals living with CRPS, inviting their members to take part.

The sample consisted of all forum members who posted messages in the 'Welcome' and 'Your thoughts and experiences' boards. A total of 24 unique usernames were identified in the dataset, comprising 23 members and 1 administrator who was involved in running the project. There was also a second administrator who posted in the researcher-led boards on the forum. Of the 60 registered members, the remaining 35 users (58.3%) were 'lurkers' who did not post any messages.

The anonymous nature of the Internet meant that demographic information about participants was limited. It was possible to obtain some information about members by examining the self-disclosed content of postings. Gender was available for all participants, comprising 5 males (21.7%) and 18 females (78.3%). Age was available for 9 participants, ranging from 20 to 54 years with a mean age of 35.6 (13.0) years. Number of years since diagnosis was available for 14 participants, ranging from 5 months to 10 years with a mean duration of 3.9 (3.5) years.

All participants lived in the UK, with the exception of one former UK resident now living in New Zealand. It was important to the study that participants were UK-based as the implications of our findings are targeted towards the NHS, and the UK context more broadly. We therefore targeted UK-based groups and social media.

2.3. Analysis

Content analysis (Elo & Kyngäs, 2008; Pfeil & Zaphiris, 2010) was used to examine the social support content of messages, using deductive (top down) analysis to code the data into existing social support categories derived from the Social Support Behavior Code (SSBC), originally developed by Cutrona and Suhr (1992, 1994) and modified for online use by Coulson and Greenwood (2012). The coding categories were operationalized using the definitions shown in Table 1. A deductive approach was used for three reasons. First, the SSBC is a standardised measure of social support that has been used in several online studies (Braithwaite et al., 1999; Coulson et al., 2007; Coulson & Greenwood, 2012; Coursaris & Liu, 2009; Mo & Coulson, 2008), making it possible to compare results across studies and build a more accurate picture of online behaviour. Second, the SSBC has been clearly operationalized. Many definitions of social support are poorly defined and operationalized, making it difficult to use them as a valid measure of social support (O'Reilly, 1988). Third, the SSBC has been divided into many subcategories of support, which provides a more complex and detailed measure of social support than what can be obtained using other coding frameworks (Braithwaite et al., 1999).

The SSBC consists of five main categories of social support that are further divided into twenty-three subcategories of support-intended communication behaviour, and has been widely used in the study of online social support. Some studies have used the five main social support categories of informational support, emotional support, esteem support, network support and tangible aid to give a broad overview of the support content of online communication (Coulson, 2005; Eichhorn, 2008; Evans, Donelle, & Hume-Loveland, 2012; Shoham & Heber, 2012), while others have used all twenty-three subcategories to obtain a more detailed examination of online social support (Braithwaite et al., 1999; Coulson et al., 2007; Coulson & Greenwood, 2012; Coursaris & Liu, 2009; Mo & Coulson, 2008).

Table 1
Social Support Behavior Code, from Coulson and Greenwood (2012), p. 872.

Support type	Definition
Informational support	
Advice	Provides ideas or suggestions for action
Referral	Refers the recipient to other sources of information or help
Situation appraisal	Helps reassess or redefine the situation being faced by the recipient
Teaching	Offers detailed information, facts or news
Emotional support	
Relationship	Conveys the importance of closeness
Physical affection	Offers physical contact, such as hugs and kisses
Confidentiality	Keeps the recipient's problem in confidence
Sympathy	Sorrow or regret for the situation faced by the recipient
Understanding/ empathy	Expressions of understanding of the situation or discloses similar experience in a way that conveys understanding
Encouragement	Provides the recipient with hope and confidence
Prayer	Offers prayer for the recipient
Esteem support	
Compliment	Says positive things about the recipient
Validation	Provides agreement with the views of the recipient
Relief of blame	Alleviates any feelings of guilt the recipient has about the situation
Network support	
Access	Provides the recipient with access to new people
Presence	Offers to be there
Companions	Reminds the recipient that there are others who share similar experiences and are available
Tangible aid	
Loan	Lend money to the recipient
Direct task	Offers to do a direct task
Indirect task	Offers to take over a task from the recipient while they are stressed
Active participation	Offers to join the recipient in an activity
Willingness	Offers or expressions of willingness to help

Data was coded in units of whole messages rather than using smaller units like individual sentences, making it possible to identify the number of forum postings that fall within each social support category. Units were coded into multiple categories instead of using mutually-exclusive categories. If two or more categories of social support were present in a single message then it was assigned to all relevant categories rather than labelling it with one category only. After reading each message several times to identify and label all instances of social support, the number of labels was counted to identify how many postings fell within each support category.

2.4. Ethical considerations

Ethical permission for this study was granted by the Universities of Nottingham and Bath, and the study was carried out in accordance with the British Psychological Society's guidelines for online research (British Psychological Society, 2013).

There are several ethical dilemmas surrounding the use of data obtained from discussion forums, particularly in relation to informed consent and anonymity (Eysenbach & Till, 2001; Robinson, 2001). As part of the registration procedure, all potential participants were informed that the forum was part of a research project and gave permission for their postings to be read and used for research purposes.

To protect the anonymity and privacy of participants, usernames and other personally identifying details have been excluded from the quoted extracts of postings. This minimises the possibility of participants being recognised from their descriptions using deductive disclosure (Kaiser, 2009; van den Hoonaard, 2003). The

Table 2
Number of messages and percentage containing social support for each month.

Month	Welcome board		Your Thoughts and Experiences board		Total	
	n	%	*n*	%	*n*	%
March 2012	1	100.0	0	n/a	1	100.0
June 2012	16	93.8	68	80.9	84	83.3
July 2012	6	100.0	18	94.4	24	95.8
August 2012	3	100.0	1	0.0	4	75.0
September 2012	12	100.0	16	87.5	28	92.9
October 2012	26	100.0	25	80.0	51	90.2
November 2012	7	85.7	16	93.8	23	91.3
December 2012	5	100.0	1	100.0	6	100.0
Total	76	97.4	145	84.1	221	88.7

Note: Messages dated March 2012 were posted by administrators before the forum was launched.

data was taken from a closed, password-protected forum, which further protects the privacy of participants by making it impossible to use an Internet search engine to trace quotes back to their original source (Kraut et al., 2004).

3. Results

Table 2 shows the number of messages posted per month on each board, together with the percentage of messages that contained at least one type of social support. The forum had high levels of activity within days of being launched, with the first month having the greatest number of messages. Activity levels fell notably during two months, August and December. The proportion of messages containing social support was consistently high across all seven months of the study.

Table 3 shows the number of forum postings in each category of social support. Overall, the most common types of social support were emotional and informational support, followed by esteem support and network support, with tangible aid being the least frequent.

3.1. Emotional support

Emotional support was present in 73.8% of postings. Five of the seven subcategories were present in the data: understanding/empathy (66.1%), physical affection (13.6%), encouragement (13.1%), relationship (5.4%) and sympathy (2.7%).

Understanding/empathy messages were the most common type of emotional support observed. Members used a high level of self-disclosure to share their stories, talk about their medical histories and how they came to be diagnosed with CRPS, and discuss the difficult and complex issues involved in living with this debilitating illness. For example:

"Hello! Am not sure if I am writing this in the right place - but here goes! I have CRPS in my left arm following a broken humerus in January 2011. It extends from my left shoulder to fingertips - and yes, I am left handed! I was lucky to be diagnosed relatively early - after 6 months - thanks to my hydrotherapist at the [hospital]. I was really grateful for this - as other people were telling me that I wasn't trying hard enough etc., even though I couldn't move my arm, shoulder and hand...! I also tried to keep my fingers moving as much as possible right from the beginning - my arm and hand were really swollen and I was worried it would all seize up. I play the piano so kept doing exercises with my hand - I'm sure this helped a lot".

[Welcome board, thread 1, message 19]

Others demonstrated their understanding by disclosing similar information about themselves, after which the first member would often post a subsequent reply giving further information. This led to a shared understanding that was expressed through a high level of empathy. Members appeared to derive great meaning from these exchanges, as this quote illustrates:

Table 3
Social support content of postings.

Support type	Welcome board		Your thoughts and experiences board		Overall	
	n	%	*n*	%	*n*	%
Emotional support	68	89.5	95	65.5	163	73.8
Understanding/empathy	57	75.0	89	61.4	146	66.1
Physical affection	19	25.0	11	7.6	30	13.6
Encouragement	14	18.4	15	10.3	29	13.1
Relationship	10	13.2	2	1.4	12	5.4
Sympathy	2	2.6	4	2.8	6	2.7
Confidentiality	0	0.0	0	0.0	0	0.0
Prayer	0	0.0	0	0.0	0	0.0
Informational support	24	31.6	53	36.6	77	34.8
Advice	11	14.5	38	26.2	49	22.2
Situation appraisal	10	13.2	17	11.7	27	12.2
Teaching	3	3.9	7	4.8	10	4.5
Referral	4	5.3	2	1.4	6	2.7
Esteem support	25	32.9	44	30.3	69	31.2
Validation	14	18.4	36	24.8	50	22.6
Compliment	13	17.1	12	8.3	25	11.3
Relief of blame	0	0.0	0	0.0	0	0.0
Network support	13	17.1	3	2.1	16	7.2
Companions	10	0.1	2	1.4	12	5.4
Presence	3	0.0	0	0.0	3	1.4
Access	0	0.0	1	0.7	1	0.5
Tangible aid	3	3.9	2	1.4	5	2.3
Direct task	2	2.6	1	0.7	3	1.4
Indirect task	0	0.0	1	0.7	1	0.5
Willingness	1	1.3	0	0.0	1	0.5
Loan	0	0.0	0	0.0	0	0.0
Active participation	0	0.0	0	0.0	0	0.0

"Thank you for your response. It gives me much hope hearing others story's".

[Welcome board, thread 1, message 34]

Physical affection was conveyed through written messages due to the text-based nature of online communities. Members exchanged affection through phrases like "Gentle hugs" (Welcome board, thread 1, message 13), while the most common affectionate gesture involved ending a message by writing "x" (e.g. Your Thoughts and Experiences board, thread 1, message 10).

Encouragement messages provided hope to members, helped to boost their confidence about achieving personal goals, and inspired them to continue with therapeutic treatments and other activities. During a discussion about hydrotherapy, when a member said that things went well until he left the water and spent the next three days in agony, others encouraged him to continue ("Stick to the hydrotherapy it is good for us I guess", Your Thoughts and Experiences board, thread 8, message 4). The importance of hope was particularly evident when one member talked in detail about her complex CRPS-related problems and her fears that she would not be able to regain control over her life. She immediately received a reply encouraging her not to give up or lose hope, saying:

"Hopefully things withh start to fall into place for you and don't give up, keep going as best you can".

[Welcome board, thread 1, message 6]

Relationship messages expressed the importance of closeness within the online community. As one member explained, "It is so lovely to see everyone supporting each other on here. It is a great idea to have a site where we can chat to others who truly understand what it is like to live with CRPS" (Welcome board, thread 1, message 46). Another member expressed similar sentiments by saying:

"Isnt strange that we live so close, with quite a lot in common, and when all this started I felt so alone, and 'its only me, know one else understands', so from that the forum has been a great idea".

[Your Thoughts and Experiences board, thread 18, message 19]

Sympathy messages expressed sorrow for the pain and distress experienced by the recipient, with a particular focus on diagnosis, symptoms and CRPS-related limitations on the type of activities that members could perform. When one member explained that she experienced seven years of agony, distress and worsening symptoms before she was diagnosed CRPS, others said how sorry they were for this ("I am sorry it took you so long to be diagnosed", Your Thoughts and Experiences board, thread 18, message 12). Similarly, when a newly joined member explained that he was finding it very difficult to cope with CRPS, he received the following reply:

"Sorry to hear you are having such a tough time at the moment".

[Welcome board, thread 1, message 68]

3.2. Informational support

Informational support was present in 34.8% of postings. All four subcategories were present in the data: advice (22.2%), situation appraisal (12.2%), teaching (4.5%) and referral (2.7%).

Advice messages were the most common type of informational support, and typically offered suggestions for coping with CRPS and managing the impact of the illness on daily life. Members urged each other to continue using the affected limb ("Even though you have not been given physio help I would suggest that you keep your foot as mobile as you can", Welcome board, thread 1, message 29), and suggested strategies like knitting or sports to keep their body active. Medication was often discussed, and members also exchanged information about disability aids that made their lives easier ("I need a stainless steel 'Spork' so as I dont need my hubbie cut my dinner up whilst in a restaurant", Your Thoughts and Experiences board, thread 18, message 1). Setting realistic and achievable goals was seen as being particularly important, as demonstrated in the following quote from an individual who initially had unrealistic expectations for what she hoped to achieve:

"Ive now set some sensible ones [goals] and that baby steps are always easiest".

[Welcome board, thread 1, message 8]

Situation appraisal messages helped members to reassess their situation, putting things into a more positive perspective. Members often urged one another to be positive and focus on the important things in life like family and loved ones ("as bad as it gets I thank god I'm here because it could have been so different I may not have been alive to see my gorgeous children grow up", Welcome board, thread 1, message 12). For some individuals, being diagnosed with CRPS and knowing the cause of their pain was a life-changing experience that helped put things into perspective and led to a deeper understanding of how CRPS can affect the whole family, as this quote indicates:

"Ive lived with this for the last 7 1/2 years and wow to be told that it wasnt in my head was such a relief and that I was normal (ish) was such a relief. From a small bang on the arm, my/our quality of life has been so badly affected, and even though I thought it was only affecting me I didnt realise how badly it was affecting the rest of the family".

[Welcome board, thread 1, message 3]

Teaching messages provided factual information about CRPS and how to use forum features like the personal messaging facility. Members discussed the prognosis for individuals diagnosed with CRPS ("CRPS pain can improve within one year after the injury, but if it is still unchanged after 12 months (longstanding CRPS), then it will often not improve at all", Your Thoughts and Experiences board, thread 1, message 21), while one member emphasised the importance of being sceptical about horror stories and other unverified sources of information on the Internet. She explained that members should only trust information that comes from reputable, evidence-based sources, saying:

"I do think some people read far too much into this kinda thing and I'm not sure it always has a positive effect on people/their illness. [...] My theory is, if it hasn't been published by a reputable source (such as Arthritis Research UK, NHS etc...) then there is a potential for the info to be unresearched or not evidenced based".

[Your Thoughts and Experiences board, thread 13, message 12]

Referral messages directed members to other sources of information. Most referrals were to Web sites and organisations that provide additional knowledge and information ("If you don't already have leaflets, the Arthritis Research site has the info from their's online I think", Your Thoughts and Experiences board, thread 6, message 3). Some referrals helped members save money when buying pet supplies or other items ("A good website for everything from beds to toys to food is [name]", Welcome board, thread 1, message 47), while one member who felt frustrated by a lack of understanding from his pain consultant was urged to seek a referral to a specialist CRPS treatment centre, as indicated in this reply:

"There are hospitals that specialise in CRPS dotted around the country. I personally attend one in [name of town] and can not praise them highly enough".

[Welcome board, thread 1, message 29]

3.3. Esteem support

Esteem support was present in 31.2% of postings. Two of the three subcategories were present in the data: validation (22.6%) and compliment (11.3%).

Validation messages agreed with the feelings of the recipient and supported their assessment of the situation. When a pain consultant told one member that he'd seen people in more pain and dismissively advised her to 'get over it', others agreed with him that this was not acceptable ("You need to be taken seriously", Welcome board, thread 1, message 29). Members sometimes expressed fears that they were 'moaning' and 'saying too much' on the forum, and others would often post reminders that it is important to express themselves and talk openly about their feelings, as illustrated in this quote:

"You go on as long as you like, Ive had a good whinge on here".

[Welcome board, thread 1, message 13]

Compliment messages expressed positive things about the recipient and what they have achieved despite suffering from CRPS. One member was complimented for successfully managing her CRPS without taking any medication ("would like to say how lucky are you", Your Thoughts and Experiences board, thread 1, message 4). In another example, when a member mentioned that she was preparing for possible inclusion in the Paralympics, others were quick to applaud her and one reply said:

"Good luck with the Paracycling assessment, what your doing is fantastic".

[Welcome board, thread 1, message 62]

3.4. Network support

Network support was present in 7.2% of postings. All three subcategories were present in the data: companions (5.4%), presence (1.4%) and access (0.5%).

Companions messages reminded members that they were not alone and that other forum members share similar backgrounds and experiences. Members were urged to express their feelings and remember that others care about them ("All I can say is for you to go with your feeling s cry if you want to scream if u need to and know that people care about you and how you are feelings", Your Thoughts and Experiences board, thread 1, message 10). In another example, a member explained the importance of being able to talk to others who have CRPS and have been through similar experiences:

"I have a family support network and friends that are supportive but even so the only people that really understand are people that have the same condition".

[Welcome board, thread 1, message 14]

Presence messages provided support by offering 'to be there' for the recipient. This type of support was typically offered when new members introduced themselves to the group. For example, when a member introduced herself and explained the difficulties she was experiencing as a result of her illness, she received the following reply:

"If I can help in anyway let me know".

[Welcome board, thread 1, message 31]

Only one *access* message was observed. During a discussion about accessibility problems and outdoor activities, two members realised they lived close to each another and one replied saying:

"[It] would be great to bump into one another".
[(Your Thoughts and Experiences board, thread 18, message 17)]

3.5. Tangible aid

Tangible aid was present in 2.3% of postings. Three of the five subcategories were present in the data: direct task (1.4%), indirect task (0.5%) and willingness (0.5%).

Direct task messages offered to do something that would directly help with a member's problem or situation. Sometimes this was expressed by offering to search for more information that might help with a problem. For example, when members were discussing pain caused by exposure to cold air and wondering whether it might be possible desensitise themselves to cold temperatures, an individual offered to help by replying:

"I will try and research some more into the cold".

[Welcome board, thread 1, message 57]

Indirect task messages were offers of help that are not directly related to a problem. For example, when a member asked how to find out how many people in the UK suffer from CRPS, he received the following reply:

"I am not sure how to find out how many people have CRPS in the UK however I will try and do some research".
[Your Thoughts and Experiences board, thread 1, message 19]

Willingness messages offered to provide help or assistance of a general and non-specific nature. For example, one message said:

"If I can help in anyway let me know".

[Welcome board, thread 1, message 31]

4. Discussion

This study investigated online social support in a newly launched CRPS discussion forum. The aim was to examine the social support content of messages, to investigate what kind of social support is present and how support processes become established.

Despite the relatively small sample size, participant demographics broadly reflected what is normally found in the CRPS population. Participants were 78.3% female and 21.7% male, which compares very closely to statistics indicating that CRPS affects four times as many females than males (de Mos et al., 2007; Sandroni et al., 2003).Participants had a mean age of 35.6 years, compared with those aged 50–70 being most at risk of developing CRPS (de Mos et al., 2007; Sandroni et al., 2003). This might be because older people are less likely to be Internet users (Office for National Statistics, 2013) and middle-aged people are more likely to use the Internet for health-related purposes (Andreassen et al., 2007; Baker, Wagner, Singer, & Bundorf, 2003; Ybarra & Suman, 2006), so one might expect forum members to be slightly younger than what is normally found in the CRPS population.

4.1. Social support

Analysis of the number of messages posted each month showed that activity levels on the forum were consistently high with the exception of two months, August and December. The reason why fewer messages were posted during those months is unclear.

Speculatively, it might simply have been because those months are associated with the summer and Christmas holidays respectively, so members could have been involved in other activities and might not have had the same amount of time for using the forum.

When a new forum is launched, there is a possibility that activity levels may increase month-by-month as members get to know one another, new members join, and the community becomes established. However, this pattern was not observed. Instead, activity levels were high during the first month with a large number of messages posted in the 'Your Thoughts and Experiences' board, and then settled into a fairly consistent number of messages per month. The percentage of messages containing social support was also consistently high. During the first month 83.3% of messages contained at least one type of social support, and most subsequent months had even higher levels of support content. Rather than needing time for support processes to become established, the provision of social support arose very quickly within the forum with members actively posting messages, introducing themselves, discussing their experiences, building relationships, responding to queries and exchanging social support. Support processes became established in a similar way to face-to-face groups, where individuals meet for the first time and begin supporting one another straight away.

Overall, 88.7% of messages contained at least one type of social support. Emotional support was the most common (present in 73.8% of messages), followed by informational support (34.8%), esteem support (31.2%), network support (7.2%) and tangible aid (2.3%).

4.1.1. Emotional support

Emotional support was present in 73.8% of messages. These messages were used to convey understanding/empathy, give physical affection, provide encouragement to help members achieve their goals, emphasise the importance of closeness in their relationships, and offer sympathy regarding symptoms and restrictions on daily activities. In particular, messages in the understanding/empathy subcategory involved high levels of self-disclosure with members sharing their personal stories and disclosing further information to demonstrate their understanding.

Previous research has shown that emotional support can be expressed using both direct and indirect statements (Winzelberg, 1997). Instead of directly and explicitly requesting support, members used indirect strategies to obtain support through self-disclosure and shared experiences (Eichhorn, 2008). This typically took the form of turn-taking where a member would post a message describing a problem, challenge or personal experience of particular concern, a second member would reply and demonstrate their understanding of the situation by disclosing their own experiences, and the first member would then respond by expanding upon their thoughts and revealing additional information about themselves and the difficulties they are experiencing (Tichon & Shapiro, 2003). This process continued cyclically, leading to high levels of emotional support through self-disclosure.

Like in other studies of online social support (e.g. Coulson & Greenwood, 2012), emotional support appeared to be particularly important and beneficial to members. Messages indicated that they felt emotionally supported through their shared backgrounds and experiences. Members often commented how important it was to have a place where they could talk openly with others who can relate to their experiences, allowing them to express feelings that their family and friends might find difficult to understand or empathise with. Hearing other people's stories gave members a sense of hope for the future, and provided them with the encouragement to continue seeking ways to live with and overcome the limitations of this unpleasant and debilitating illness.

4.1.2. Informational support

Informational support was present in 34.8% of messages. These messages were used to provide advice on managing the impact of CRPS on daily life, helped members reappraise their situation to focus on the important things in life, taught them to use the forum more effectively and consider the trustworthiness of online information, and referred members to Web sites and other external sources of information.

These lower levels of informational support together with higher levels of emotional support are consistent with the predictions of Optimal Matching Theory (Cutrona & Suhr, 1994). According to this theory, the controllability of a situation plays an important role in determining what kind of social support will be most beneficial to the individual. It proposes that individuals with controllable problems should benefit most from informational support because they can use this information, advice and guidance to help them deal with the cause of their difficulties. However, those with uncontrollable problems should benefit more from emotional support because this will help them to cope with unpleasant emotions and stressful negative effects of being in an uncontrollable situation.

For individuals with chronic CRPS that has failed to resolve itself, treatment is palliative and involves helping the individual learn how to control and self-manage their illness (Rodham et al., 2012, 2013). Participants used informational support to help with the controllable aspects of living with CRPS like the use of disability aids, while emotional support was important for the uncontrollable aspects of living with a chronic illness that does not have a cure. Several previous studies investigating online social support for health conditions like cancer (Coulson & Greenwood, 2012; Turner et al., 2001), eating disorders (Eichhorn, 2008), infertility (Malik & Coulson, 2008a, 2008b), irritable bowel syndrome (Coulson, 2005) and physical disability (Braithwaite et al., 1999) have also supported Optimal Matching Theory.

4.1.3. Esteem support

Esteem support was present in 31.2% of messages. These messages were used to validate the feelings of other members by encouraging them to express themselves openly and support each other's decisions, and to compliment members on their achievements.

This type of social support was typically offered spontaneously, making it the third most common type of social support within the forum. This is consistent with Optimal Matching Theory, which predicts that esteem support is important in both controllable and uncontrollable situations. For individuals faced with an uncontrollable problem, esteem support can reduce the negative impact of a stressful situation by reassuring the individual of their worth and reminding them that they are not to blame (Cutrona & Suhr, 1994). Esteem support was typically offered in response to the high levels of self-disclosure within the forum, making it closely linked to the emotional support content of postings. The most important function of esteem support was validating the messages posted by other members, indicating that the shared experiences of forum members puts them in a unique position to understand and comment upon the difficulties of living with a chronic illness on a daily basis (Coulson et al., 2007).

4.1.4. Network support

Network support was present in 7.2% of messages. These messages reminded members that they are not alone in their experiences, and emphasized the presence of other members who could support the individual in their struggle with the disease.

Individuals with chronic CRPS can become socially isolated and withdrawn due to the unpleasant and debilitating nature of their symptoms, with difficulties participating in social and recreational

activities (Galer et al., 2000) and a reduced social network through which to obtain support (Rodham et al., 2009). Network support may be particularly important for individuals with a restricted social network because their networking needs may need to be fulfilled through the online community to offset feelings of loneliness, isolation and alienation in their everyday lives (Braithwaite et al., 1999).

This makes it surprising that network support was one of the least prevalent support categories in this study, with levels much lower than those reported in communities for HIV/AIDS (Coursaris & Liu, 2009; Mo & Coulson, 2008) and Huntington's disease (Coulson et al., 2007). However, it emerged that participants were using the CRPS forum alongside other social media platforms like Facebook and Twitter. Even though participants used the forum to fulfil many of their emotional and informational support needs, this meant that they did not need to rely on the forum for their networking needs because those needs were already being fulfilled through other outlets, and hence levels of network support were lower than expected. This shows that newly launched online support communities do not all develop in the same way, instead it depends on the unique and individual needs of members who join these communities, and also their wider social media use.

4.1.5. Tangible aid

Tangible aid support was present in 2.3% of messages. These messages offered to provide direct help to overcome a situation, indirect help that is not directly linked to a problem, or expressed a general willingness to provide help if requested.

These low levels of tangible aid are typical of what has been found in other studies (Coulson et al., 2007; Coursaris & Liu, 2009; Mo & Coulson, 2008) and may be due to the limitations of online communication. The lack of face-to-face contact between members restricts the opportunities to provide this type of practical assistance to help with problems, so tangible aid was limited to the kinds of tasks that can be conducted over the Internet like searching for information or offering to exchange private messages.

4.2. CRPS four pillars of intervention

These results indicate that social support received by taking part in forums and other types of online community may play an important role in the CRPS 'four pillars of intervention' (Turner-Stokes & Goebel, 2011), which focus on education, pain relief, rehabilitation and psychological intervention.

First, education is needed to help members learn more about CRPS, what treatment options are available, how to self-manage the illness, and how their own behaviour can influence pain levels. The informational support received through the forum served a range of educational purposes. Individuals received factual information about CRPS, practical advice on a range of topics that helped them to cope with the illness and minimise its impact on everyday life, and they also used the forum to discuss treatment options, set goals and review their progress. Esteem support was used to compliment members on their achievements.

Second, pain relief may be needed to control pain levels and, in turn, to help the individual sleep. Informational and emotional support messages on the forum were of great benefit in relation to this, with members discussing pharmacological interventions, invasive treatments, and specialist pain management courses. They talked about their medication regimes and whether or not they had found those drugs helpful for controlling pain levels, their experiences of undergoing invasive treatments like spinal cord stimulation, and the benefits of attending specialist inpatient courses to help them learn how to control their pain levels. This

was particularly beneficial for helping individuals learn more about potential options for pain control, and it gave them a realistic appraisal of how effectively each option might work based on other people's experiences.

Third, physical and vocational rehabilitation should be used to restore normal functioning in the affected limb and alleviate the negative social and financial impacts of not working. Informational, emotional and esteem support messages were important in physical rehabilitation, with members exchanging information and advice about desensitization, exercise techniques and disability aids that they found helpful to restore and maintain physical functioning, and validating each other's views as well as providing encouragement. Emotional support was important for the vocational aspects of CRPS, with individuals discussing both the challenges that CRPS posed in their working lives and also the difficulties that some individuals faced if they were no longer able to work.

Fourth, psychological interventions are used to address other factors that contribute to pain and disability. Informational, emotional and esteem support messages were all used to discuss negative problems, coping strategies, and the importance of staying positive and focussing on the important things in life, while network support reminded members that they are not alone in their struggles with the illness. These are all likely to have contributed to the improved psychological wellbeing of members.

4.3. Limitations & future research

There were several limitations in this study, which lead to a number of suggestions for future research. First, just over half the registered members (58.3%) were 'lurkers' who did not post any messages. This is typical of what is often found in health-related online communities, where the number of 'lurkers' can range from 0% to 99% with a mean of 45.5% (Nonnecke & Preece, 2000). Of the 23 participants who posted forum messages, 17 (73.9%) were low frequency posters who posted less than the mean of 9.5 messages per participant, while the remaining 6 (26.1%) were high frequency posters. These high frequency posters were responsible for most of the forum content, creating 57.9% of threads and writing 75.1% of messages. This indicates that they were core members who played an important role in initiating and sustaining discussions, providing support and answering questions.

Some previous studies have noted the presence of core members in virtual communities. For example, Letourneau et al. (2012) distinguished between nonusers, moderate users and high users in a study of online support for asthma and allergies using chat sessions, where nonusers were comparable to 'lurkers' and provided little usable data, moderate users took part in three or four chat sessions, and high users formed a core group who took part in at least five chat sessions. Core groups have also been reported in online communities for breast cancer (Høybye, Johansen, & Tjørnhøj-Thomsen, 2005), clinical depression (Muncer, Loader, Burrows, Pleace, & Nettleton, 2000) and older people (Pfeil, Svangstu, Ang, & Zaphiris, 2011). In the present study, the presence of a core group meant that a large part of the dataset was generated by a relatively small subgroup of participants. It is difficult to determine how closely the data from these core members represents the experiences of all participants in the study, or how well these results would generalise to other online communities.

Second, although the SSBC coding framework has been used in many studies of online social support, it should be noted that the SSBC was not originally developed for online use. The SSBC was devised for analysing face-to-face supportive interactions between spousal couples (Cutrona & Suhr, 1992, 1994) and has subsequently been adapted for online use (e.g. Coulson & Greenwood,

2012). In the present study the SSBC coding categories produced a good fit with the data, with 88.7% of messages coded into the SSBC categories. The remaining 11.3% of messages discussed off-topic issues like the names of songs they were currently listening to, and did not have any social support content. Some studies have noted that there can be instances where it is difficult to apply the SSBC to online data because it is not always easy to make the fine distinctions needed between some of the coding subcategories (Braithwaite et al., 1999). Additionally, there are differences between online and face-to-face social support, which means that there could be important elements of online support that are not included in the SSBC categories. This has led some researchers to advocate using inductive (bottom up) coding strategies to examine the social support content of online communities (Coulson & Greenwood, 2012; Hwang et al., 2010). While an inductive approach would overcome many of these limitations, it also introduces other challenges because the results would lack standardisation and make it more difficult to compare findings across studies.

Third, these results are only applicable to individuals with Internet access, but Internet access is not equally distributed across the population. In the UK, older people, females and the disabled are all less likely to be Internet users (Office for National Statistics, 2013). Even in countries with high levels of Internet use, user typologies indicate that most of the population can still be categorised as non- or occasional-users (Brandtzæg, Heim, & Karahasanović, 2011; Selwyn, Gorard, & Furlong, 2005). This limits the range of people who are likely to benefit from using online support communities.

Internet user typologies (Brandtzæg et al., 2011; Selwyn et al., 2005) have distinguished between several different types of Internet user, such as sporadic, instrumental, entertainment and advanced users. Little is known about how these different types of Internet user engage with online support communities. For example, it is possible that instrumental or advanced users might be more likely to join an online support community than sporadic or entertainment users, and different types of Internet user might use online support communities in different ways and hence derive different benefits from community membership. Research investigating the role of user typologies in online communities may lead to a greater understanding of who uses online communities and how they benefit from them.

Fourth, this study was conducted using a closed forum that offered high levels of privacy by requiring members to register with a username and password before accessing the community to read messages. It is difficult to determine how important privacy was to members in the study. Future research may be needed to investigate the role of privacy in open and closed online communities, and how this influences the decision to join or take part in these groups.

Fifth, in this newly launched online community, support processes started almost immediately. However, it is uncertain whether this is unique to this particular group, to groups dedicated to supporting individuals with CRPS, to closed groups generally, or if support processes become established this way across all online communities. Further research investigating what happens when new forums are launched will help to build a clearer picture of how support processes become established and what role this might play in distinguishing between successful groups and those that fail to prosper. Longitudinal research may help to establish if and how support processes change and evolve over time. Additionally, there is a need for research using online support communities whose members are drawn from other national and cultural backgrounds, and who may communicate using alternative languages instead of English, to determine how well these findings generalise to other types of online community.

5. Conclusions

Social support can play an important role in the wellbeing of individuals with CRPS, who may become socially isolated as a result of their illness. Online support communities are valuable and important resources that make it possible for individuals with CRPS to interact with others and obtain social support over the Internet. The forum messages in this study were found to contain high levels of social support that helped with both the controllable and uncontrollable aspects of living with CRPS.

Online social support may have an important role to play in the CRPS 'four pillars of intervention' (Turner-Stokes & Goebel, 2011), which focus on education, pain relief, rehabilitation and psychological intervention. These findings indicate that online support may help with the educational aspects of disease management through access to factual information about CRPS, setting goals for themselves and discussing their progress with other members. Discussions about medications may help with pain relief, while advice about desensitisation, physical exercise, disability aids and coping strategies could help with rehabilitation and improved functioning. Finally, having access to social support, realising that they are not alone in their struggle, and focussing on positive thinking and the important things in life could assist with the psychological aspects of living with CRPS by promoting more appropriate patterns of thought and behaviour.

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