ONLINE SOCIAL SUPPORT FOR COMPLEX REGIONAL PAIN SYNDROME

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Abstract

Individuals living with Complex Regional Pain Syndrome (CRPS) often experience difficulties taking part in social and recreational activities, which can leave them with a greatly reduced social network and limited opportunities for obtaining social support. Online support communities may provide individuals with an alternative way of obtaining social support, but few studies have examined these communities in the context of CRPS. Furthermore, most online support community research has focussed on established communities, and little is known about how new communities become established. This thesis examines a bespoke CRPS online support community with two broad aims: to examine the development of online support processes in relation to the launch of a new online support community, and to investigate the provision of social support for CRPS within an online support community. The dataset comprised 221 messages posted by 23 participants. Study 1 used the full dataset to examine engagement with the online support community, focussing on the number of individuals who used the forum (membership growth), how they used it (header analysis) and how they introduced themselves (introductory messages). Study 2 used the full dataset to investigate how support processes became established, the support content of messages, and how this contributed to the CRPS '*four pillars of intervention*'. Study 3 used four longitudinal case studies from the dataset to conduct a linguistic analysis of messages, focussing on support providing behaviour and the number of replies received. The results indicate that support processes start almost immediately when a new online support community is launched, and membership growth is closely linked to promotional strategies. Online support may play an important role in CRPS self-management by contributing to the '*four pillars of intervention*', and there is a possibility that diffusion of responsibility may occur in forums. The longitudinal case study approach may produce important new insights and

suggests that the use of health words is unrelated to the number of replies received, the use of self and other-oriented messages may be linked to health status and support providing activities, and that the ratio of positive-to-negative words could potentially be used to identify individuals who might benefit from additional support.

List of publications

Chapter 2

Coulson, N., & Smedley, R. (2015). A Focus on Use of Online Support. In A. Attrill (Ed.), *Cyberpsychology* (pp. 197-213). Oxford: Oxford University Press.

Chapter 5

Smedley, R., Coulson, N., Gavin, J., Rodham, K., & Watts, L. (in press). Engagement in a newly launched online support community for Complex Regional Pain Syndrome: membership growth, header analysis and introductory messages. *International Journal of Web Based Communities*.

Chapter 6

Smedley, R., Coulson, N., Gavin, J., Rodham, K., & Watts, L. (2015). Online social support for Complex Regional Pain Syndrome: A content analysis of support exchanges within a newly launched discussion forum. *Computers in Human Behavior*, *51* Part A, 53-63.

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Away from university I must thank my parents and Dr John Porter for their support, patience and encouragement. Finally, and most importantly, I owe a huge debt of gratitude to my late uncle, John Fletcher (1954-2009), who died far too young after a long battle with a rare illness. Without his incredible generosity, none of this would have been possible.

Author's declaration

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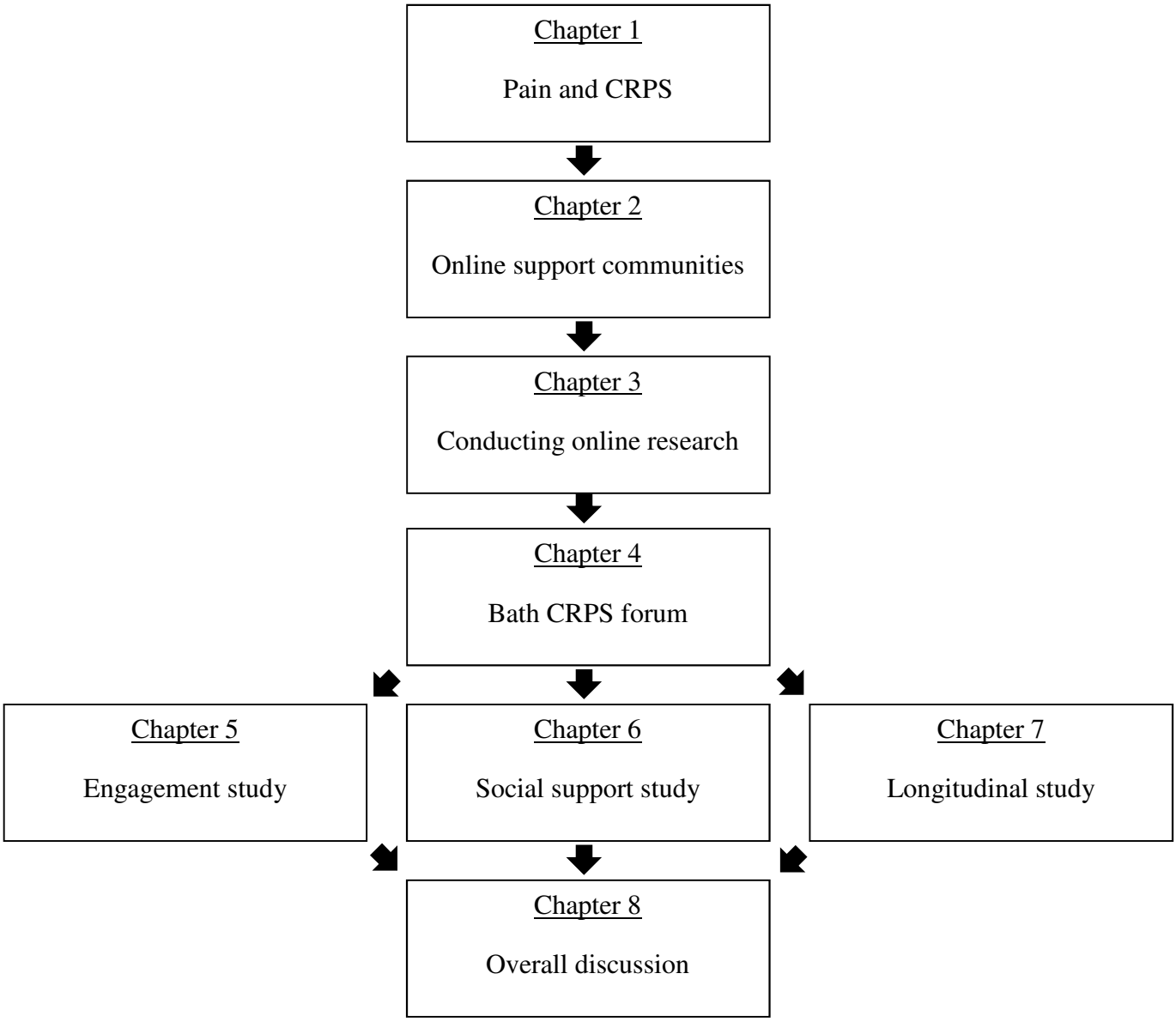
I was not involved in the design or running of this wider project. Through my supervisor, an opportunity arose where all members of the research team granted permission giving me full retrospective access to the dataset after the project was completed. I had complete freedom to make my own decisions about what studies I would like to conduct, the rationale behind them, and how to use and analyse the data. The literature review, studies, research questions and data analysis presented in this thesis are entirely my own work, and were carried out independently of the original project. Members of the research team looked at the nearly finished drafts of my empirical publications and commented on them because they were grant holders to the original project, but they did not shape or influence my work.

Contents

Thesis structure



Chapter 1: Complex Regional Pain Syndrome

Abstract

This chapter reviews the literature on pain and Complex Regional Pain Syndrome (CRPS). It explores definitions, components, types and characteristics of pain, how pain signals are transmitted within the body, and theoretical approaches to pain. It then considers CRPS in relation to its background and incidence rate, how this condition is diagnosed and treated, and the challenges experienced by individuals living with this condition.

1.1 Pain

1.1.1 Definitions of pain

The word '*pain*' is commonly used to describe either the conscious experience of bodily injury or the unpleasant feelings associated with negative emotions (Perl, 2007). The Subcommittee on Taxonomy of the International Association for the Study of Pain (IASP) provide a formal definition of pain, defining it as "*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*" (Merskey et al., 1979, p. 250).

Although the IASP definition is regarded as being the best definition of pain (Loeser & Melzack, 1999), it has attracted some debate and controversy in the literature. It has been argued that the IASP definition may be unethical because it relies on the verbal self-report of pain, which could mean that people and animals who are unable to communicate how much pain they are experiencing may not receive the same level of pain assessment and prevention as others (Cunningham, 1999). However, others have defended the IASP definition by pointing out that it captures the essence of pain by focussing on the subjective nature of pain as a multi-dimensional phenomenon that is influenced by sensory, emotional and cognitive processes (Derbyshire, 1999).

In evolutionary terms, pain reflects damage or a perceived threat to biological integrity and has both sensory and emotional components (Chapman & Gavrin, 1999). Having a sensory awareness of tissue integrity plays a crucial role in survival and adaptation to the local environment, whilst the emotional experience of pain reflects how important the damaged area is to the individual. When pain continues beyond the initial tissue damage, it can stop being an aid to survival and instead contributes to disability and suffering (Chapman & Gavrin, 1999).

1.1.2 Components of pain

Loeser and Melzack (1999) distinguish between four broad components of pain: nociception, pain perception, suffering, and pain behaviours.

1.1.2.1 Nociception

Nociception refers to the neural process of detecting tissue damage through pain receptors that are sensitive to changes beyond a certain threshold. This can be relieved by using drugs like aspirin to restore nociceptive sensitivity, and local anaesthetics work by preventing the transmission of nociceptor signals to stop nociception turning into pain (Loeser & Melzack, 1999).

1.1.2.2 Pain perception

Pain perception relates to the subjective awareness of pain. This is influenced by a range of psychological and contextual factors including the age, gender and learning of the individual, their expectation of pain relief, their perceived level of control, and how significant the pain is to that individual (McGrath, 1983). Pain can be triggered by noxious stimuli such as disease, injury, or nervous system lesions like those seen in individuals with stroke or diabetic neuropathy, and it is possible for pain to occur in the absence of nociception (Loeser & Melzack, 1999).

1.1.2.3 Suffering

Suffering occurs when there is perceived damage to the self, impairing a person's ability to do things that they think they should be able to do. Suffering is a broader concept than pain with more dimensions and a greater number of potential causes. Pain does not always cause suffering, and suffering can be caused by a range of other phenomena in addition to pain (Chapman & Gavrin, 1999).

1.1.2.4 Pain behaviours

Pain behaviours refer to observable actions performed by an individual in response to pain, which would enable an observer to recognise that they are in pain. These behaviours can include somatic interventions like taking painkillers or seeking medical advice, impaired functioning like reduced movement and avoidance of activities, and pain complaints like moaning and contorted facial expressions (Frederiksen, Lynd, & Ross, 1978).

1.1.3 Types of pain

Several different types of pain have been identified in the literature, including neuropathic and musculoskeletal pain, transient, acute and chronic pain, and organic and functional pain.

1.1.3.1 Neuropathic and musculoskeletal pain

Neuropathic pain refers to pain caused by lesions or other changes to parts of the central or peripheral nervous system that normally signal pain, and arises in medical conditions like phantom limb pain (caused by lesions in the peripheral nervous system), multiple sclerosis (lesions in the central nervous system) and Complex Regional Pain Syndrome (a complex neuropathic disorder) (Freynhagen & Bennett, 2009).

Musculoskeletal pain refers to pain associated with muscles, bones and joints, and is associated with a range of conditions like rheumatoid arthritis, back pain and foot pain (Bergman, 2007).

Headaches can fall into both categories, with tension headaches caused by musculoskeletal problems while migraine headaches are a type of neuropathic disorder (Biondi, 2004).

1.1.3.2 Transient, acute and chronic pain

Transient pain is also known as episodic or breakthrough pain, and is difficult to define (Mercadante et al., 2002). In the context of cancer treatment it refers to transitory bursts of severe pain that can last for anything from a few minutes to three or four hours, which may be caused by coughing, moving in bed, or by opioid drugs wearing off before the next dose is scheduled to be delivered (Portenoy & Hagen, 1990). Transient pain can also refer to the everyday aches and pains that individuals experience as a normal part of their daily life without needing to seek medical care, or the brief pain that is sometimes associated with undergoing a medical procedure like an injection (Loeser & Melzack, 1999).

Acute pain occurs when illness, injury, surgery or other forms of tissue trauma trigger a nociceptor response that will generally subside within a few weeks (Carr & Goudas, 1999). Most individuals with acute pain will seek medical care, and the pain usually stops long before the trauma is fully healed (Loeser & Melzack, 1999). Acute pain can be treated using a range of analgesic drugs including opioids and local anaesthetics, and also through psychological interventions like distraction (Carr & Goudas, 1999). Although chronic illnesses and malignant diseases can cause continuing acute pain (Carr & Goudas, 1999; Loeser & Melzack, 1999), pain lasting for months or years is not normally classed as being acute (Loeser & Melzack, 1999).

Chronic pain refers to pain that continues beyond the expected course of an acute disease process, and is usually defined as pain that lasts for more than six months (Russo & Brose, 1998). However, what distinguishes between acute and chronic pain is not the duration of pain but the body's inability to restore normal physiological functioning (Loeser & Melzack, 1999). Chronic pain like back pain or fibromyalgia may initially be triggered by disease but the nature of the injury, loss of body parts or nervous system damage can all prevent the body from restoring normal functioning (Loeser & Melzack, 1999). All individuals with chronic pain will seek medical care (Loeser & Melzack, 1999), but chronic pain can be difficult to treat. It is likely that chronic pain will have failed to respond to previous attempts at treatment, and the unrelenting pain can have a major impact on the individual's life and lead to illness behaviours that may exacerbate the problem (Russo & Brose, 1998).

1.1.3.3 Organic and functional pain

Organic pain refers to pain that is caused by some form of identifiable tissue damage, while *functional pain* occurs in individuals who do not have any demonstrable organic disease (Leavitt, Garron, D'Angelo, & McNeill, 1979).

1.1.4 Characteristics of pain

Researchers have examined the words used by people to describe the quality of pain that they experience, which can then be categorised into pain characteristics.

In one of the first studies of its type, Melzack and Torgerson (1971) reviewed the clinical literature and developed a list of 102 pain-related words, which they organised into three major categories and thirteen sub-categories identifying various different qualities of pain. The sensory qualities of pain consisted of nine sub-categories: temporal (e.g. pulsing, throbbing); spatial (e.g. darting, shooting); punctate pressure (e.g. penetrating, stabbing); incisive pressure (e.g. cutting, sharp); constrictive pressure (e.g. cramping,

squeezing); traction pressure (e.g. tugging, wrenching); thermal (e.g. burning, scalding); brightness (e.g. stinging, tingling) and dullness (e.g. aching, numbing). The affective qualities of pain comprised four sub-categories: tension (e.g. exhausting, tiring); autonomic (e.g. nauseating, suffocating); fear (e.g. dreadful, terrifying) and punishment (e.g. torturing, vicious). Finally, the evaluative qualities referred to words describing the overall subjective intensity of pain (e.g. mild, unbearable).

Tearnan and Cleeland (1990) found that people with cancer used 129 different words to describe their pain, which they categorised according to semantic similarity to form eleven word categories: dullness (26% of words, e.g. ache, dull); punctate pressure (12%, e.g. stabbing, thrusting); constrictive pressure (11.4%, e.g. pressure, cramping, pressing); incisive pressure (11.2%, e.g. sharp); periodicity (8%, e.g. steady, continual); thermal (7.6%, e.g. burning); tenderness (5.5%, e.g. hurts, sore); temporal (4.2%, e.g. throbbing); spatial (3.5%, e.g. shooting); traction (2.9%, e.g. pulling, twisting), and location (1.2%, e.g. deep, surface).

In a more recent study, Dudgeon et al. (2005) found that people with physical disabilities such as lower limb amputation or cerebral palsy used many different words to describe their pain, and categorised them into the three main categories identified by Melzack and Torgerson (1971): pain sensation (e.g. aching, cramping, sharp-stabbing); pain affect (e.g. tiring-exhausting, nagging-bothersome), and temporal aspects of pain (e.g. steady-constant, comes and goes). Across all disabilities, words that were frequently used to describe pain included aching, tingling, throbbing, stabbing, cramping and stinging.

The words used to describe pain may be important for pain assessment because some words like sharp, stabbing and unbearable are indicative of severe pain and hence can be used as a measure of pain intensity (Tearnan & Cleeland, 1990).

1.1.5 Pain pathways

This section considers the physiology of pain. An examination of how pain signals are transmitted within the body will provide a foundation from which to consider theories of pain and the complex relationship between the brain, central nervous system, psychological processes and our subjective perception of pain.

A-Delta and C type afferent neurons[1] are used to transmit pain signals to the brain, and A-Beta neurons also form an important part of pain circuitry because of their role in suppressing pain. A-Delta and C type receptors are widely found in the skin, membranes, connective tissues, muscles, arterial vessels and other parts of the body, with painful sensations occurring when nociceptors are activated by mechanical, thermal or chemical stimuli (Almeida, Roizenblatt, & Tufik, 2004). Mechanical stimuli cause physical deformation of bodily structures (e.g. trapping your hand in a door), thermal stimuli refer to hot and cold temperatures (e.g. frostbite), and chemical stimuli can arise internally or externally (e.g. muscle pain caused by a build-up of lactic acid, or having your body exposed to a noxious substance) (Sufka, 2000).

These A-Delta, A-Beta and C neurons are discussed further in Section 1.1.6.2, where they are considered in the context of gate control theory.

1.1.6 Theories of pain

There have been three major stages in the development of pain theories: classical theories like specificity and pattern theories, the '*middle ages*' of gate control theory, and modern theories that extend these earlier accounts based on findings from neuroimaging and other technologies (Price & Sufka, 2006).

[1] In the peripheral nervous system, afferent neurons transmit sensory information *to* the central nervous system and efferent neurons carry signals *from* the central nervous system to muscles and glands (Sufka & Price, 2002).

1.1.6.1 Classical theories

Classical theories of pain were developed prior to 1965, and focussed on one or two aspects of pain based on an imperfect clinical and anatomical understanding of pain (Price & Sufka, 2006).

Perl (2007) explains that theories of pain have a long history dating back to the ancient Greeks. Aristotle (384–322 BC) argued that pain is an emotion originating from the heart, just like all other emotions. A few centuries later the physician Galen (AD 129–c. 200) realised that feelings originate from the brain and that pain is a sensation rather than an emotion. The philosopher Avicenna (AD 980–1037) noted that pain is an independent sensation dissociated from other sensations like the sense of touch.

Until the 1950s the predominant theory of pain was based on Descartes' *specificity theory*, which was developed in the 17th century (Benini & DeLeo, 1999; Melzack, 1993). Descartes was inspired by Galileo's use of the scientific method to study the physical laws of the universe, which led Descartes to propose that human bodies are similar to clockwork machines and can be studied in a purely mechanistic way. Descartes' specificity theory of pain proposes that when a bodily injury occurs, specific pain receptors in the skin transmit pain signals directly to the brain (Benini & DeLeo, 1999). The subjective experience of pain was thought to be directly related to the physical injury, with no possible route for pain perception to be influenced by psychological mechanisms like attention (Melzack, 1993). Descartes' theory suggested that severing pain pathways should alleviate pain, although causing damage to pain pathways often produces the opposite effect by exacerbating existing painful conditions (Benini & DeLeo, 1999).

Attempts to develop a new pain theory led to the emergence of several *pattern theories* of pain (Melzack, 1993). These theories propose that individual afferent neurons respond to different types of stimulation by producing different patterns of impulses (Nielson, 2001).

However, the focus of this approach is on peripheral neurons rather than the central nervous system (Nielson, 2001) and, like with specificity theory, the brain is assumed to passively receive these pain signals without playing any role in interpreting them (Melzack, 1993).

1.1.6.2 The '*middle ages*'

The '*middle ages*' of pain theories began in 1965 and extended into the 1980s, when *gate control theory* led to a more comprehensive understanding of pain (Price & Sufka, 2006).

Gate control theory (Melzack & Wall, 1965) revolutionised the study of pain by recognising the role of the brain and central nervous system in pain perception (Dickenson, 2002; Melzack, 1996). It proposes that pain signals are moderated by a gating mechanism located in the dorsal horns of the spinal cord, where pain signals from A-Delta and C neurons tend to open the gate while inhibiting signals from A-Beta neurons tend to close the gate. The gating mechanism is also influenced by neural pathways descending from the brain, which can open or close the gate. The extent to which the gate is open or closed influences the transmission of pain signals to the brain. This means that psychological processes like attention play a central role in pain perception (Melzack, 1996).

Most of the basic tenets of gate control theory have been supported by extensive research, but one limitation is that the theory may be too general because interactions in the dorsal horn appear to be more complicated than was originally envisaged (Sufka & Price, 2002). Overall, gate control theory has changed how scientists, researchers and clinicians think about pain, and it continues to produce new insights into pain management through an improved understanding of pain transmitters and receptors (Dickenson, 2002). It has also been described as having an important influence on patient care by encouraging clinicians and nurses to take a more holistic view of people who are in pain, which means that pain

control strategies are now implemented in situations where it was previously assumed that the individual was responding to emotional states like anxiety, depression or the anticipation of pain (VandenBosch, 1986).

1.1.6.3 Modern theories

Modern theories of pain were developed from the 1980s onwards, and extend earlier theories of pain by looking at brain structures and the neuroanatomy of pain (Price & Sufka, 2006). For example, *neuromatrix theory* arose from an examination of pain and other phenomena associated with phantom limbs, where individuals continue to experience parts of the body after they have been amputated or after the nerve connections to those areas have been severed (Melzack, 1989). The neuromatrix is a conceptualisation of the central nervous system comprising a widespread network of neurons that use parallel processing across different areas of the brain to create an inner representation of the whole body, which processes information about different parts of the body even when those areas do not physically exist or when all sensory input has been lost. Sensory information about injuries is sent to the brain and triggers a complex series of events intended to restore homeostasis, with output patterns from the neuromatrix producing the sensory, affective and cognitive dimensions of pain. If attempts to restore homeostasis fail then this can lead to neuromatrix patterns that cause further tissue damage and lead to chronic pain (Melzack, 2005). However, while neuroimaging studies have shown that several different areas of the brain are involved in pain processing, neuromatrix theory has been criticised for being too vague about how these regions perform particular pain-related functions and how neuromatrix pathways might potentially be modified to treat pain disorders (Derbyshire, 2000).

1.2 Complex Regional Pain Syndrome

This section will look at an unpleasant pain condition called Complex Regional Syndrome (CRPS). Before examining this condition, it is necessary to briefly consider whether individuals with CRPS should be referred to as '*patients*'.

According to Herxheimer and Goodare (1999), the word '*patient*' is difficult to define and carries many negative connotations. They explain that it is commonly used to describe an individual who seeks advice or treatment from a healthcare professional, and highlight numerous problems associated with this. First, being a patient implies that the individual endures suffering while waiting to be seen and also suggests that the individual has a lower status in the doctor-patient relationship, qualities that may not reflect the realities of being a healthcare recipient. Second, many people consult healthcare professionals when they are not ill, such as when seeking family planning advice or undergoing preventative measures like immunization, and it may not be appropriate to describe these individuals as patients. Third, describing somebody as a patient can involve labelling them with a disease while ignoring their unique personal characteristics, for example it is more desirable to refer to somebody as '*a person with cerebral palsy*' than '*a spastic*'.

Consequently, this thesis avoids using the word '*patient*' and instead adopts the term '*individuals living with CRPS*'. The word '*suffering*' is also avoided for similar reasons (the concept of suffering is briefly examined in Section 1.1.2.3). Only the individual can state whether their symptoms cause them to experience suffering, so they should not be described as '*suffering from symptoms*' because this involves making unwarranted assumptions about their experience of living with the illness. Instead they are described as '*individuals who have particular symptoms, challenges and difficulties*'.

1.2.1 What is 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).

McCabe and Blake (2008) illustrate the strange and disparate range of symptoms that can be associated with the disease by describing a case report of a female who developed CRPS following a severe viral infection in her mouth. Two months after the viral infection was successfully treated, she experienced pain in her left hand that gradually extended upwards to her elbow. Her lower arm was swollen and felt very hot, the colour of her skin fluctuated between a mottled version of her normal skin colour and dusky purple, and she described a burning pain that was exacerbated by touch or movement. She also had abnormal nail growth and loss of hair around the painful site. Merely approaching the affected limb without touching it would trigger an increase in pain levels, so she was very protective of her arm and avoided social situations out of fear that other people might '*knock into*' it. With her eyes closed, she perceived her left hand as being much larger than her right, and found it difficult to identify individual fingers when they were touched. The individual described her lower arm as being '*alien*' and wanted to have it amputated, and she could identify the exact point where her '*real*' arm ended and the '*alien*' part started.

1.2.1.1 History

The history of CRPS can be traced back to at least the American Civil War (Hassantash, Afrakhteh, & Maier, 2003; McCabe & Blake, 2008). Originally, the illness was known by a confusing variety of names that had become so indiscriminately used that they no longer had any clear meaning, so CRPS was introduced as an umbrella term to provide uniform

diagnostic criteria for these closely related pain syndromes (Chaplan & Sorkin, 1997; Stanton-Hicks et al., 1995). Symptoms typically develop following an injury to the affected area but they can also arise spontaneously (McCabe & Blake, 2008).

1.2.1.2 Types of CRPS

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.

CRPS Type 1 has been known by many different names including Sudeck's atrophy, post-traumatic dystrophy and, more frequently, reflex sympathetic dystrophy (Albazaz, Wong, & Homer-Vanniasinkam, 2008; van Eijs et al., 2011). The condition typically develops following minor trauma like a bone fracture, and the onset of symptoms can occur straight away but more usually arise within a month of the trauma or a limb being rendered immobile by a plaster cast (McCabe & Blake, 2008).

CRPS Type 2, formerly known as causalgia, is a much rarer condition. In their meta-analysis, Hassantash et al. (2003) described it as being mainly a wartime disease with causes including fractures (1% of cases), non-penetrating injuries (5%) and gunshot wounds (7%), with at least 77% of cases associated with some form of high-velocity impact. The onset of pain can occur immediately or up to a month or more following the initial injury. Symptoms include burning pain (86% of individuals), increased sweating (73%) and sensitivity to foreign stimuli (98%).

Additionally, a third type of CRPS has been proposed called *Not Otherwise Specified (NOS)* for individuals who only partly meet the diagnostic criteria and whose symptoms cannot be better explained by making any other diagnosis (Harden et al., 2007).

It is also possible to distinguish between warm and cold CRPS according to skin temperature at the time of onset. Individuals with warm CRPS have reddish skin and a higher skin temperature, while those with cold CRPS have bluish skin and their skin temperature is unaffected (Eberle et al., 2009). Dystonia (movement disorders like tremors or fixed posture) only occurs in individuals with cold CRPS, those with cold CRPS are also more likely to have other chronic pain disorders like headaches and back pain (Eberle et al., 2009) and have a medical history of asthma, migraines or osteoporosis (de Mos et al., 2008). Motor weakness is more prevalent in warm CRPS, and warm CRPS usually turns into cold CRPS as the condition becomes chronic (Eberle et al., 2009). Individuals who are initially diagnosed with the cold variant of CRPS were found to experience worse clinical outcomes in an eight-year follow-up study, with increased central nociceptive sensitisation and more pain as assessed by the McGill Pain Questionnaire (Vaneker, Wilder-Smith, Schrombges, de Man-Hermsen, & Oerlemans, 2005).

1.2.2 Incidence rate

The first study to investigate the incidence rate[2] of CRPS was conducted by Sandroni, Benrud-Larson, McClelland, and Low (2003), who examined medical records for the population of Olmsted County in Minnesota, United States of America (USA), a largely rural area with a 95% white non-Hispanic population. Examination of 106,470 medical records covering the period 1989-1999 revealed 74 cases of CRPS, indicating an incidence rate of 5.46 new cases per year for every 100,000 people in the population. However, this study has been criticised because they only looked at individuals living in one geographical area, they had to rely on sign and symptom data to retrospectively decide whether each individual met the criteria for a potential CRPS diagnosis, and their

[2] Incidence refers to the number of new cases diagnosed in a given time period, and prevalence refers to the total number of individuals with an illness at a particular point in time (Shields & Twycross, 2003).

figures may have been affected because the IASP diagnostic criteria for CRPS were changed in 1994 midway through the period they were examining (Bruehl & Chung, 2007).

More recently, de Mos et al. (2007) conducted a population study by examining electronic patient records from 52 general practitioners across the Netherlands. A total of 217,653 records were examined covering the period 1996-2005 by initially searching for keywords and prescriptions associated with CRPS and then using follow-up questionnaires with General Practitioners (GPs) to confirm whether potential CRPS cases had a genuine diagnosis. This led to the identification of 238 cases, suggesting an incidence rate of 26.2 new cases per 100,000 annually.

Both studies agreed that women are approximately four times more likely to be diagnosed with CRPS than men, the incidence of CRPS is highest amongst those aged 50-70, and it most commonly affects the upper limbs of the body (de Mos et al., 2007; Sandroni et al., 2003). Initiating events have been identified as fractures (49% of individuals), soft tissue injuries such as sprains (20%), surgery (11%), tendon injuries (6%) and other types of injury (6%), with 8% of cases occurring spontaneously with no precipitating event, while individuals with a medical history of asthma, migraine headaches, osteoporosis and cycle-related menstrual disorders appear to be at increased risk of developing the illness (de Mos et al., 2008).

The disease has a high resolution rate, with 74% of cases recovering within twelve months of diagnosis (Sandroni et al., 2003). However, little is known about factors that predict a poor prognosis for individuals diagnosed with CRPS. Brunner, Nauer, and Bachmann (2011) investigated this by conducting a survey of clinicians and academics with at least two CRPS-related publications, asking them to list and rate factors associated with poor outcomes. They found that a poor prognosis is believed to be associated with

both clinical and non-clinical factors. Important clinical factors were various sensory, motor and autonomic changes, having CRPS on upper body regions, the disease developing spontaneously or being initiated by a fracture, and illness duration of more than three months. Non-clinical factors were not having a social network, someone or something having caused the problem, and disease-related conflict with an employer. Unfortunately it is not clear what the authors meant by '*someone or something having caused the problem*' and '*disease-related conflict with employer*' because Brunner et al. do not define, clarify or expand upon these phrases. It appears that their results should be treated tentatively because it is unclear how much knowledge and expertise the survey respondents had with CRPS, so these results could be based partly on extensive clinical experience and partly on personal opinion, guesswork, or limited experience with small numbers of non-representative individuals.

1.2.3 Diagnosis

There are no scans or medical tests that can be used to diagnose CRPS so diagnosis is based on clinical criteria (Turner-Stokes & Goebel, 2011), although laboratory tests may sometimes be used to rule out other conditions as part of the diagnostic process (Albazaz et al., 2008). Several diagnostic criteria have been developed for use with CRPS, which differ in the type and number of signs and symptoms[3] that need to be present for a diagnosis to be made.

The *Veldman criteria* (Veldman, Reynen, Arntz, & Goris, 1993) outlines three requirements for diagnosis. First, the individual should have at least four of the following: unexplained diffuse pain, differing skin colour compared with other limbs, diffuse oedema (i.e. swelling or puffiness of the skin due to fluid retention), differing skin temperature compared with other limbs, and a limited active range of motion. Second, the

[3] Symptoms are phenomena arising from a disease, and signs indicate a particular meaning such as a diagnosis or prognosis (King, 1968).

above signs and symptoms should either occur or increase after use. Third, the signs and symptoms should be present in a larger area than that of the primary injury.

The *IASP criteria* (Stanton-Hicks et al., 1995) outlines four requirements for diagnosis. First, the condition should develop following either a noxious event like a fracture (Type 1) or following a nerve injury (Type 2). Second, spontaneous pain should be present in a wider area than the initial injury and be disproportionate to that event. Third, the area of the pain should show current or past evidence of oedema, abnormal skin blood flow, or abnormal sudomotor activity (i.e. sweating). Fourth, the individual cannot be diagnosed with any other conditions that might better explain the pain and dysfunction that they are experiencing.

The *Bruehl criteria* (Bruehl et al., 1999), designed for research use, outlines three requirements for diagnosis. First, the individual must have ongoing pain that is disproportionate to any initiating event. Second, they must have at least one symptom in each of the following four categories: sensory (hyperesthesia, i.e. increased sensitivity to stimuli), vasomotor (changes in skin colour, asymmetrical skin colour, asymmetrical skin temperature), sudomotor/oedema (oedema changes, sweating changes, sweating asymmetry), motor/trophic (reduced motion, motor dysfunction, changes in hair, skin or nails). Third, they must have at least one sign in two or more of the previously-mentioned categories.

The *Budapest criteria* (Harden et al., 2007), designed for clinical use, outlines four requirements for diagnosis. First, the individual must have ongoing pain that is disproportionate to any initiating event. Second, they must have at least one symptom in three of the following four categories: sensory (hyperesthesia or allodynia, i.e. increased sensitivity to stimuli or increased pain response to stimuli), vasomotor (changes in skin colour, asymmetrical skin colour, asymmetrical skin temperature), sudomotor/oedema

(oedema changes, sweating changes, sweating asymmetry), motor/trophic (reduced motion, motor dysfunction, changes in hair, skin or nails). Third, they must have at least one sign in two or more of the previously-mentioned categories. Fourth, the individual cannot have an alternate diagnosis that better explains their signs and symptoms.

These criteria all have varying degrees of overlap. The Veldman criteria is often used in the Netherlands (van Eijs et al., 2011), the IASP criteria is the most sensitive (van Eijs et al., 2011) and is internationally recognised (de Mos et al., 2007), while the Bruehl and Budapest criteria benefit from high specificity (van Eijs et al., 2011). In the United Kingdom (UK), the Budapest criteria is used to diagnose CRPS (Goebel, Barker, & Turner-Stokes, 2012).

1.2.4 Treatment

Chronic CRPS is a difficult condition to treat, partly because little is understood about the underlying causes of the illness (Bruehl, 2010). A range of potential treatment strategies have been investigated, with some reviews focussing exclusively on CRPS type 1 (Hord & Oaklander, 2003; Perez et al., 2010) while others examine treatment evidence for both type 1 and type 2 CRPS (Cossins et al., 2013).

1.2.4.1 Drug treatments

Drug treatments are often used to control pain, but evidence for the effectiveness of this approach is mixed. There is no evidence to indicate that paracetamol is effective as a standalone treatment for CRPS (Perez et al., 2010). The use of anaesthetics like ketamine can significantly reduce pain levels (Cossins et al., 2013; Perez et al., 2010) and corticosteroids appear to be effective for reducing inflammation and decreasing pain (Hord & Oaklander, 2003; Perez et al., 2010). However, there is insufficient evidence regarding the use of non-steroidal anti-inflammatory drugs (NSAIDs) like ketorolac to control pain (Perez et al., 2010). The anticonvulsant drug gabapentin may be effective at

reducing neuropathic pain (Hord & Oaklander, 2003; Perez et al., 2010) but there is no evidence for other anticonvulsants (Perez et al., 2010). There is also insufficient evidence to support the use of opioids or antidepressants (Cossins et al., 2013; Perez et al., 2010).

1.2.4.2 Invasive treatments

Spinal cord stimulation can reduce long-term pain and also improve quality of life but it does not lead to improvements in functioning (Cossins et al., 2013; Hord & Oaklander, 2003; Perez et al., 2010). Amputation is sometimes used in individuals with severe complications but there is little evidence that it can be used as an effective method of treatment (Perez et al., 2010). Surgical sympathectomy to cut nerves in the sympathetic nervous system may be effective at relieving pain (Perez et al., 2010) but it remains unclear whether it is effective at providing long-term relief (Cossins et al., 2013).

1.2.4.3 Paramedical interventions

Physiotherapy and mirror therapy are effective at reducing pain and should be started at an early stage following diagnosis (Cossins et al., 2013; Perez et al., 2010). However, there is little evidence to support the use of Transcutaneous Electrical Nerve Stimulation (TENS) when reducing pain (Perez et al., 2010). Occupational therapy may help to reduce pain and improve the severe functional limitations associated with CRPS (Hord & Oaklander, 2003; Perez et al., 2010). However, once again, there is little evidence to indicate that psychological interventions are likely to be effective (Perez et al., 2010), although clinicians should remember that individuals with CRPS may experience problems with anxiety or depression as a consequence of their illness (Hord & Oaklander, 2003).

1.2.4.4 Self-management

The main goal of treatment and rehabilitation is to help individuals self-manage their condition (Rodham, Boxell, McCabe, Cockburn, & Waller, 2012). Specialist inpatient

rehabilitation programmes comprising physiotherapy, occupational therapy, hydrotherapy and also sessions with clinical and health psychologists may be particularly beneficial to help individuals self-manage their CRPS.

According to Rodham et al. (2012), being offered a place on a rehabilitation programme can be a turning point for individuals who may have previously felt as if they were floundering alone and unable to cope with the illness. This programme provided a sense of relief at finding healthcare professionals who believe them, and meeting other individuals with similar feelings and experiences also helped the individual to accept that their CRPS is real and not just in their mind. However, these courses can also be a mixed experience because returning home afterwards means losing access to experts and specialist facilities, which may make it difficult for some individuals to continue receiving the help they need.

1.2.4.5 Four pillars of intervention

The '*gold standard*' for CRPS treatment is an interdisciplinary approach using the '*four pillars of intervention*' (Goebel et al., 2012; Turner-Stokes & Goebel, 2011), which focus on education, pain relief, rehabilitation and psychological interventions.

First, *education* should be provided to help individuals learn about their illness, how pain levels can be affected by their own behaviour, treatment options that are available, and how to self-manage their CRPS. This can be achieved through the provision of information leaflets, and also by engaging with healthcare professionals to set goals and discuss appropriate treatments (Turner-Stokes & Goebel, 2011). In particular, information leaflets may be used to inform individuals about CRPS and what it is like living with the illness, and describe some of the treatments methods that might potentially be used, while discussions with specialists will help the individual to set goals and review their progress,

and also promote insight into how their behaviour can impact upon pain levels (Goebel et al., 2012).

Second, *pain relief* medications and procedures may be considered to help manage pain levels and assist in maintaining sleep patterns. As described earlier in this section, a range of pharmacological interventions could potentially be used but the evidence for their effectiveness is mixed (Cossins et al., 2013; Hord & Oaklander, 2003; Perez et al., 2010). Currently there is only preliminary evidence for CRPS pain relief and no drugs are licensed in the UK for treating this illness, so medications should be administered according to specialist guidelines for neuropathic pain (Goebel et al., 2012).

Third, *physical and vocational rehabilitation* can be used to restore normal functioning in the affected limb. Physical rehabilitation can involve using a range of techniques including retraining the body to encourage the individual to maintain a normal posture, addressing altered perceptions of the affected limb through mirror therapy, and normalising the sense of touch using thermal and tactile desensitisation (Goebel et al., 2012). Vocational rehabilitation may also benefit the individual by helping them to either stay in or return to work (Goebel et al., 2012), and avoid the financial and psychosocial difficulties associated with not working (Kemler & Furnée, 2002).

Fourth, *psychological interventions* may be used to address other issues that contribute to pain and disability. Individuals with chronic pain are at increased risk of depression and anxiety (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997), and may benefit from specialist intervention to treat these difficulties. Psychologists can also help the individual to recognise the importance of staying positive, develop better coping skills, and identify maladaptive behaviours and counter-productive family dynamics that may be having an impact on the illness (Goebel et al., 2012; Turner-Stokes & Goebel, 2011).

1.2.5 Living with Complex Regional Pain Syndrome

The impact of CRPS and the challenges associated with this condition will be considered in terms of the impact on the individual, the impact on others in the household, the financial consequences of CRPS, and the importance of social support.

1.2.5.1 Impact on the individual

Section 1.2.1 describes the symptoms that are typically experienced by individuals living with CRPS. The illness can adversely affect several aspects of daily life, and it is important for individuals to self-manage the illness. They may also experience disturbed sleep, cognitive impairments and depression, all of which can adversely affect their quality of life. Each of these issues will now be examined more closely.

Self-management: CRPS cannot be cured so self-management forms a vital part of living with the condition. According to Rodham, McCabe, Pilkington, and Regan (2013), there are three important components of learning how to control CRPS: acceptance, support, and being informed. First, it is vital to accept the illness, recognise that it cannot be cured, and avoid making unrealistic expectations or wanting things to change too quickly.

Second, having the right kind of support is crucial. Many individuals find themselves isolated from their previous circle of friends, so support needs to come from people who understand CRPS and empathise with the problems associated with it. Building a new support network is an important part of taking control of CRPS. Having a supportive and understanding GP is also vital because medical practitioners act as gatekeepers for ongoing care and specialist referrals.

Third, it is important for individuals to educate themselves as much as possible about CRPS, which can normalise symptoms that could otherwise be unsettling. Sometimes individuals may use the Internet to learn more about their condition, but this is not always

perceived as being a source of good quality information because of the potential exposure to misleading descriptions and worse-case scenarios.

Disturbed sleep: It is estimated that as many as 65%-88% of individuals living with chronic pain experience difficulty sleeping (Morin, Gibson, & Wade, 1998; Smith, Perlis, Smith, Giles, & Carmody, 2000). Pain interferes with both the onset and maintenance of sleep, such that it takes longer to fall asleep, they wake up more frequently during the night, and they spend less time sleeping (Morin et al., 1998). Reduced sleep is associated with increased mortality (Gallicchio & Kalesan, 2009), impaired emotional functioning (Beattie, Kyle, Espie, & Biello, 2015), excessive sleepiness during the daytime (Bartlett, Marshall, Williams, & Grunstein, 2008), and cognitive impairments that may lead to memory problems and difficulty with concentrating or making decisions (Fortier-Brochu, Beaulieu-Bonneau, Ivers, & Morin, 2012).

Smith and Haythornthwaite (2004) concluded that there could be a reciprocal relationship between chronic pain and disturbed sleep, which may exacerbate the difficulties experienced by individuals with illnesses like CRPS. In addition to pain causing sleep disturbances as described above, the resulting poor sleep has an additional adverse effect on the individual by causing them to experience greater levels of pain the next day.

Cognitive impairments: 54% of individuals with chronic pain report that they have at least one type of cognitive impairment, with common difficulties including: forgetfulness (23.4% of respondents); having minor accidents (23.1%); difficulty finishing things they have started (20.5%); being unable to maintain their attention on activities (18.7%); finding it difficult to concentrate and think clearly (17.2%), and making mistakes when doing things (15.4%) (McCracken & Iverson, 2001).

These attentional deficits, memory problems and other issues can make it difficult for individuals to engage with everyday tasks, with one theory suggesting that pain detracts cognitive resources away from other stimuli that would otherwise require attention (Moriarty, McGuire, & Finn, 2011). Additionally, some of the medications that are used to treat chronic pain may themselves cause cognitive impairments as a side-effect of taking them (e.g. Schiltenwolf et al., 2014).

Depression: The National Collaborating Centre for Mental Health (2010) explains that depression is a mental health problem characterised by low mood, the absence of positive emotions and other symptoms including irritability, tearfulness, social withdrawal, and diminished activity. Individuals with depression often experience changes in their sleep patterns and eating habits, they may have recurring negative thoughts about themselves, and feelings of helplessness or worthlessness. They estimate that between 4% and 10% of adults will experience major depression at some point during their lifetime.

A high proportion of individuals with chronic pain also have depression, with most studies reporting prevalence rates of between 30% and 60% (Magni, 1987). These individuals are more likely to have an increased pain severity, a greater degree of pain-related interference when performing normal activities, and they also display more pain behaviours like grimacing or showing distress compared with their non-depressed counterparts (Haythornthwaite, Sieber, & Kerns, 1991). Depression appears to occur as a consequence of living with pain, indicating that being in pain causes their depression (Fishbain et al., 1997).

Quality of life: The concept of quality of life has become increasingly important within healthcare (Moons, Budts, & De Geest, 2006), yet there is considerable debate and uncertainty regarding how this phrase should be defined, used and operationalised (for overviews, see Mandzuk & McMillan, 2005; Moons et al., 2006). Generally, quality of

life can be thought of as a subjective, multi-dimensional construct concerned with how individuals appraise their own lives, how satisfied they are with their physical, social and psychological functioning, and how others make objective evaluations about their well-being (Mandzuk & McMillan, 2005).

Living with pain is acknowledged to negatively affect quality of life (Mandzuk & McMillan, 2005), and the CRPS-related difficulties and challenges described above appear to have a major impact on quality of life. Among individuals with CRPS who have a moderate-to-severe pain intensity, around three quarters report that the illness causes substantial interference on general activities, mood, normal work, recreational activities and social activities, and around two thirds also report that it interferes with mobility, relationships, sleep and enjoyment (Galer, Henderson, Perander, & Jensen, 2000).

1.2.5.2 Impact on others in the household

CRPS has an impact on all members of the affected household. Chronic pain can have a dysfunctional effect on families because partners may use ineffective coping strategies that can exacerbate pain problems instead of alleviating them (Snelling, 1994).

Lauder, McCabe, Rodham, and Norris (2011) interviewed carers who support individuals with CRPS. Carers were usually the spouse or partner of the affected individual, although occasionally the carer could be a parent or close friend. The study revealed how the illness becomes a part of carer's lives even though they find some aspects of the condition difficult to understand. They reported that many carers use the Internet to search for information about the condition, to help them develop a better understanding of the illness and look for possible treatments. This helps carers to be involved in three elements of supporting individuals with CRPS. First, carers encourage the individual to engage with rehabilitation without pushing so far that it is perceived as nagging them. Second, carers who attended specialist appointments with the individual found that this helped them to

be more actively involved in rehabilitation by increasing their understanding of what might help. Third, the level of support that carers can provide depends on the individual's willingness to let them be actively involved in the rehabilitation process. This can be a cause of frustration for some carers if the individual tries to compensate for their lack of control over the illness by being too controlling about rehabilitation.

1.2.5.3 Financial consequences

Households where one adult has CRPS experience a loss of income and also face changes in the weekly activities undertaken by individuals and their spouses (Kemler & Furnée, 2002). This study in the Netherlands found that households where the male has CRPS experienced a loss of income of $4,000 per year despite female partners working more to compensate for the male no longer being able to work, and 60% hired domestic help at a further cost of $1,600 per year. Males with CRPS spent less time in paid employment, while their female partners spent more time on housekeeping and less time on personal needs and leisure activities. Households where the female has CRPS experienced a loss of income of $2,000 per year, with 74% hiring domestic help at a further cost of $1,250 per year. Females with CRPS spent less time in education or paid employment and more time on household maintenance, while their male partners (like the female partners of males with CRPS) spent more time on housekeeping and less time on personal needs and leisure activities.

Household incomes can themselves have health-related consequences. In their review, Benzeval et al. (2014) identified four main pathways through which money affects well-being: material mechanisms, psychosocial pathways, behavioural pathways and reverse causation. First, *material mechanisms*: Money is necessary to pay for key necessities in life such as housing, heating and good quality nutritional food. Individuals with less money are more likely to live in poor-quality housing with damp problems, mould and

animal/bacterial infestations; they may lack of outdoor space, and live in worse areas where there is noise, pollution or antisocial behaviour.

Second, *psychosocial pathways*: Having a low income is stressful in its own right, and individuals may have less social support to help them cope with their situation. Additionally, social comparison with others who have more money or a higher social status can also produce feelings of distress.

Third, *behavioural pathways*: Socially-disadvantaged individuals are more likely to engage in negative health behaviours, by smoking or drinking to help them cope with their difficult circumstances. If they are having problems coping then they may be less likely to think about the long-term consequences of their behaviour.

Fourth, *reverse causation*: Having poor health can make it more difficult for the individual to obtain paid employment, which has an impact on the next generation of the family. Poor housing and lack of resources limits the social and educational opportunities that are available to their children, restricting their potential job opportunities and future earnings.

1.2.5.4 Importance of social support

As previously described, it is crucial for individuals with CRPS to have the right kind of social support in order to take control of their illness (Rodham, McCabe, et al., 2013). Perceived levels of social support have been shown to reduce the amount of pain experienced the following day, as well as helping to reduce negative moods, depression and feelings of anger (Feldman, Downey, & Schaffer-Neitz, 1999). However, individuals with CRPS may find themselves becoming socially isolated and withdrawn. CRPS substantially interferes with an individual's ability to participate in social and recreational activities (Galer et al., 2000), and it can leave them with a drastically reduced network

through which they can obtain support (Rodham, McCabe, & Blake, 2009). Building a new support network is an important part of learning how to control and self-manage the illness (Rodham, McCabe, et al., 2013).

Over the past twenty years there has been a huge increase in the number of households with Internet access. In 1998 it was estimated that only 9% of UK households had an Internet connection, but by 2015 this had increased to 86% of households (Office for National Statistics, 2015a). The growing popularity of the Internet, together with the development of new technologies such as online support communities[4], has created new opportunities for individuals living with a health condition such as CRPS to obtain information and social support (Leung, 2008; Powell, Darvell, & Gray, 2003). Whereas individuals could previously only obtain support by talking to a healthcare professional or sharing their concerns with family and friends, it is now possible for individuals to use discussion forums and other social media outlets (e.g. Facebook) on the Internet to connect with others who face similar health problems (Coulson, 2013; Holbrey & Coulson, 2013; Hughes & Hans, 2001). This represents a new opportunity for individuals who might not have access to support to now obtain it, by interacting with others who understand what it is like to live with a particular illness and have been through similar experiences.

This means that social support received over the Internet by participating in online support communities may be particularly beneficial to individuals with CRPS. Unfortunately, there has been little research investigating online social support for CRPS. Rodham et al. (2009) explored how individuals use an online support community for CRPS by examining the content of messages posted by members, and found that discussions focussed around needing to stay positive, venting their frustrations over the

[4] Online support communities are interactive online services that enable individuals with a particular health condition to communicate by reading messages and posting replies (Malinen, 2015).

negative impact of living with CRPS, the importance of giving and receiving support, and their hopes and anxieties about whether hospitals will ever be able to provide a cure for their illness. However, while this study gives an important insight into the use of online support communities, much remains unknown. It is unclear what kind of social support members receive by participating in these communities, or how that support changes and develops over time.

1.3 Summary

Pain is an unpleasant sensory experience that plays a vital role in survival and adapting to the local environment, but when pain continues beyond the initial tissue damage it can contribute to disability and suffering. Theoretical approaches to pain like gate control theory and neuromatrix theory show how pain has sensory and emotional components, allowing psychological processes like attention to play a role in pain perception.

Chronic Regional Pain Syndrome is an unpleasant and debilitating condition that has a major impact on the daily lives of individuals and their families. Having the right kind of social support is crucial but individuals may find themselves socially isolated. Receiving social support over the Internet through online support communities may be particularly beneficial to individuals with this illness.

Chapter 2: Online support communities

Abstract

This chapter reviews the literature on the Internet and online support communities. First, it provides background information concerning the Internet and describes socio-demographic predictors of Internet use. Second, health-related Internet use is examined by looking at health-related activities that can be performed on the Internet. Third, online support communities are defined and discussed, considering the different types of community, their advantages and disadvantages, who uses them, what members talk about, and levels of engagement. Fourth, it considers theoretical approaches to online support communities and social support that is received over the Internet.

2.1 The Internet

2.1.1 What is the Internet?

The Internet is the most widely used computer network in the world (Glowniak, 1998; Leiner et al., 2009) and is the latest in a long line of technological breakthroughs that have each had a profound impact upon society and interpersonal communication, ranging from the invention of the telegraph through to the development of mass broadcast technologies like radio and television (Bargh & McKenna, 2004).

The origins of the Internet are difficult to trace because the Internet arose from forty years of technological development that took place simultaneously in several countries throughout the world. One of the early precursors of the Internet was developed in 1969 when the Advanced Research Projects Agency (ARPA) funded a project to link four computers at separate institutes in the USA, creating a network called ARPAnet. As additional computers were added to the system, computers in a single institution formed their own Local Area Networks (LANs) and in some cases several LANs were themselves connected together into Wide Area Networks (WANs), which then connected

to ARPAnet. These interconnected networks eventually became collectively known as the Internet (Glowniak, 1998; Kleinrock, 2010; Leiner et al., 2009).

2.1.2 Usage statistics

As of December 31, 2014 it is estimated that 42.4% of the world's population are Internet users: Internet use is high in Europe (70.4% of the population) and North America (86.9%), and much lower in regions like Africa (27.5%) and the Middle East (48.1%) (Internet World Stats, 2015). Within Europe, as of June 30, 2014, Internet use is higher in countries like Sweden (94.8%), Norway (95.1%) and the UK (89.8%), and lower in Spain (74.8%) and Italy (58.5%) (Internet World Stats, 2014).

In the UK, government statistics indicate that 86% of households have Internet access, 88% of adults have used the Internet at least once during the last three months, and 78% of adults use the Internet every day. A diverse range of activities are performed on the Internet with 76% of adults using e-mail, 76% using online shopping, 69% finding information about goods and services, 61% using social networking, and 49% looking for health-related information. Overall, 94% of households with Internet access use a broadband connection, and less than 1% use dial-up Internet access (Office for National Statistics, 2015a).

The Office for National Statistics (2015b) also publish reports into socio-economic differences in Internet use in the UK, with statistics indicating that younger people are more likely to use the Internet than older people, men are more likely to use the Internet than women, and disabled people are less likely to use the Internet. In particular, their statistics on Internet use by disabled people indicate that 27.4% of disabled adults have never used the Internet, compared with only 6.6% of non-disabled adults (Office for National Statistics, 2015b).

In addition to the research previously described, which looks at who uses the Internet by using the '*digital divide*' to distinguish between Internet users and non-users (Gunkel, 2003; Tsatsou, 2011), an additional body of literature has examined differences in how people use the Internet. Selwyn, Gorard, and Furlong (2005) identified four categories of Internet user: non-users (58% of overall sample, have not used the Internet in the past year); occasional users (11%, occasionally used the Internet); narrow frequent users (18%, used the Internet frequently but only for one or two purposes), and broad frequent users (13%, used the Internet frequently and for three or more different purposes). Brandtzæg, Heim, and Karahasanović (2011) identified five types of Internet user: non-users (42% of sample, do not use the Internet regularly); sporadic users (18%, occasional and infrequent use of the Internet for specific tasks like e-mail or information searching); entertainment users (10%, high level of Internet use for e-mail, information seeking and recreational activities like downloading or playing games and music); instrumental users (18%, medium level of Internet use for goal-orientated tasks like online banking, Internet shopping and searching for information), and advanced users (12%, high level of Internet use covering a wide and varied range of purposes, primarily oriented towards instrumental rather than leisure activities).

2.2 Health-related Internet use

2.2.1 What people do online

The Internet plays an important role in a wide range of daily activities ranging from online shopping, banking, learning new things, staying in contact with family and friends, and leisure activities such as playing games and listening to music, through to seeking help and support for health-related problems (Leung, 2008). There are so many health-related resources on the Internet that Morahan-Martin (2004) described it as being the world's largest medical library. The Internet provides access to a huge number of health-

related websites as well as government health sites, professional organisations, academic journals, medical citation databases, mailing lists, online support communities and also health-related information that is received through targeted advertising and e-mail spam messages (Morahan-Martin, 2004).

Health-related Internet use originally involved three main types of activity: searching for information, taking part in online support communities and interacting directly with healthcare professionals (Cline & Haynes, 2001). Subsequent technological developments have expanded this into a more diverse range of activities that also includes buying medications, ordering prescriptions and booking appointments online (Andreassen et al., 2007), accessing medical records over the Internet (Pyper, Amery, Watson, & Crook, 2004), and using social networking sites like Facebook to follow the health status of friends (Thackeray, Crookston, & West, 2013).

2.2.1.1 Searching for health-related information online

Information seeking typically involves using an Internet search engine like Google to search for health-related information (Morahan-Martin, 2004). Most people seeking health information look for information for themselves or somebody they know after being diagnosed with a specific medical condition, to find out about a new medication or treatment that they have been prescribed, because they are dealing with an on-going illness, if they have unanswered questions after a medical consultation, or to find out about lifestyle changes such as deciding to change their diet or exercise regime (Morahan-Martin, 2004). Other reasons for searching for health information can include accessing performance reports, choosing a clinician or selecting a healthcare provider (Cline & Haynes, 2001). Information may come from scientific and institutional websites as well as those created by individuals who range from being well informed to those who lack credibility or promote dubious treatments (Cline & Haynes, 2001).

Following a successful search, online health information may trigger feelings of anxiety or reassurance (Andreassen et al., 2007), prompt the individual to make a medical appointment or seek a second opinion, and be used to help make treatment decisions (Morahan-Martin, 2004). However, the downsides of seeking online health information include having to sift through large amounts of information, finding information that is difficult to understand, feeling overwhelmed, becoming aware of conflicting medical opinions, and confusion about the best approach to treatment (Arora et al., 2008; Keselman, Browne, & Kaufman, 2008; Longo et al., 2010; Morahan-Martin, 2004).

2.2.1.2 Taking part in online support communities

Taking part in online support communities and interacting with healthcare professionals are somewhat distinct from information seeking because they both involve using the Internet for health-related communication (Rains, 2008). However, online support communities offer an alternative to professional care and have similarities with face-to-face support groups, creating an environment where individuals can obtain social support and information, and share their experiences with other like-minded individuals (Cline & Haynes, 2001). These support communities are available at any time and provide individuals with access to a wider range of opinions and experiences than would otherwise be possible, but they may also expose group members to undesirable attention and antisocial behaviour (White & Dorman, 2001). Online support communities will be examined in more detail in Section 2.3.

2.2.1.3 Interacting with healthcare professionals

Interacting with healthcare professionals typically involves using e-mail to communicate with either a doctor who is known to the individual or a Web doctor with whom there has been no previous contact (Cline & Haynes, 2001). E-mail can be used to facilitate various aspects of doctor-patient communication including answering questions and providing

information, avoiding gaps in communication and reducing unnecessary appointments (Mechanic, 2001). However, research suggests that only 6% of Internet users have used e-mail to communicate with a doctor or other healthcare professional, compared with 25.5% who have used e-mail to discuss health issues with family and friends (Baker, Wagner, Singer, & Bundorf, 2003).

2.2.1.4 Accessing medical records

Individuals can also use the Internet to access their own medical records. While not everybody wants to see their medical records, providing online access to them has numerous potential benefits like encouraging people to take a greater interest in their health, checking that their records are complete and up-to-date, clarifying why medications have been prescribed, and helping them to self-monitor conditions or provide additional information like living wills (Pyper et al., 2004). Online medical record systems of this type have been used in countries like Denmark (Kierkegaard, 2011) and the USA (Hassol et al., 2004), and the European Commission plans to implement a similar system across the whole of Europe by the year 2020 (Kierkegaard, 2011).

2.2.1.5 Following the health status of others

Individuals may also seek health information through social networking sites like Facebook or Twitter, which enable people to share information and follow the health experiences of friends. It appears that most social networking users prefer to read information provided by others, with only 15.2% of users contributing information of their own. The reasons why so few people contribute their own experiences on social networking sites might be because contact with health professionals may only occur relatively infrequently, or they do not feel sufficiently knowledgeable about health topics and prefer to leave discussions to the professionals (Thackeray et al., 2013).

2.2.1.6 CRPS health-related Internet use

Little is known about health-related Internet use by individuals with CRPS. Chapter 5 looks at how individuals with CRPS engage with online support communities, and Chapter 6 shows how these communities can play an important role in the CRPS '*four pillars of intervention*' (discussed in Section 1.2.4.5).

2.3 Online support communities

2.3.1 What are online support communities?

Online support communities (also known as '*online health communities*' or '*online support groups*') have been defined as being "*online services with features that enable members to communicate with each other*" (Malinen, 2015, p. 228). They provide a dynamic environment where individuals can interact with others, learn how other people have dealt with problems, '*vent*' about their difficulties and experiences without worrying loved ones, and receive support, comfort and companionship (Attard & Coulson, 2012; Chen, 2014; Coulson, 2013; Malik & Coulson, 2008b). One of the unique aspects of online support communities is that they rely exclusively on members to both generate and consume content (Malinen, 2015), that is to say, these communities exist so that members can use them to interact with others by posting messages and reading replies.

Individuals may use online support communities to give, receive and exchange social support (Coulson, 2005; Coulson, Buchanan, & Aubeeluck, 2007; Coulson & Greenwood, 2012; Coursaris & Liu, 2009; Mo & Coulson, 2008). Online social support can be defined as "*the cognitive, perceptual, and transactional process of initiating, participating in, and developing electronic interactions or means of electronic interactions to seek beneficial outcomes in health care status, perceived health, or psychosocial processing ability. It incorporates all components of traditional social*

support, with the addition of entities, meanings, and nuances present in a virtual setting, and unique to computer-mediated communication" (LaCoursiere, 2001, p. 66).

Membership is typically defined as anyone who takes part in the community by posting messages, and can also include '*lurkers*' who read messages written by other people without posting any messages of their own (Ridings & Gefen, 2004). However, defining who is a member can be complicated. For example, somebody could join a community by registering as a member but only use the site a small number of times, or use it for a while and then stop using it entirely. Such an individual would be counted as a member if their username is still registered on the system, even though they might not perceive themselves as being a member and they no longer use the community (see Malinen, 2015).

2.3.2 Types of online support community

Many online support communities are for individuals living with a specific medical condition like Complex Regional Pain Syndrome (Rodham et al., 2009), diabetes (Loader, Muncer, Burrows, Pleace, & Nettleton, 2002), hearing loss (Cummings, Sproull, & Kiesler, 2002) or Parkinson's disease (Attard & Coulson, 2012). However, there are also online support communities covering a range of other topics including bereavement communities that help individuals to overcome the death of a loved one (van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2010), health behaviour communities that focus on behaviour change such as helping people to lose weight (Bane, Haymaker, & Zinchuk, 2005), parent communities for individuals who are raising children with illnesses like autism (Carter, 2009), and communities to support caregivers like those who run childcare groups (Worotynec, 2000) or who provide unpaid support to elderly or ill relatives, friends and neighbours who are unable to perform tasks for themselves (Tanis, Das, & Fortgens-Sillmann, 2011).

There are two broad types of online support community, single-function communities and comprehensive communities (Finfgeld, 2000). Single-function communities consist of a standalone interactive community without any additional services, to provide an environment where individuals with shared concerns can exchange information and support. Membership is voluntary and members can join or leave when they want. In contrast, comprehensive communities offer a range of additional services that could also include encyclopaedia-style reference materials, tools to assist with decision making, and individually tailored help. Some of these communities were created by researchers to investigate how computers and online resources can be used to enhance healthcare services, so membership may be invitation-only with members encouraged to continue participating until the study is completed (e.g. Gustafson et al., 2001).

Online support communities can be based on several different technologies including World Wide Web discussion forums (e.g. Attard & Coulson, 2012), Usenet newsgroups (e.g. Loader et al., 2002), e-mail ListServs (e.g. Cummings et al., 2002) and chat rooms (e.g. Letourneau et al., 2012). Discussion forums have become the most prevalent type of online support community, and have numerous advantages like being easy to access, the ability to search through archives of previous messages that have been posted, and the straightforward use of emoticons (Barak, Boniel-Nissim, & Suler, 2008). Alternatively, online support communities can be created within popular social networking sites such as Facebook (e.g. Bender, Jimenez-Marroquin, & Jadad, 2011; Greene, Choudhry, Kilabuk, & Shrank, 2011).

It is also possible to distinguish between online support communities that are synchronous and asynchronous in time (Murray, 2000; Robinson, 2001). Synchronous communities provide a dynamic environment with content that is constantly changing from one moment to the next, allowing individuals to engage in live, real-time conversation with

other members. Examples of this include chat rooms and instant messaging (Robinson, 2001) and online virtual reality environments (Beard, Wilson, Morra, & Keelan, 2009).

In contrast, asynchronous communities provide a more static environment with content that changes less frequently; after posting a message it could potentially take anything from a few minutes to a number of months before receiving a reply (Attard & Coulson, 2012; Barak et al., 2008; Robinson, 2001). It is not possible to engage in live conversation within asynchronous communities, but instead they let people read messages when it is convenient and allow individuals to take their time while composing replies. Examples of this include discussion forums, e-mail ListServs and Usenet newsgroups (Robinson, 2001).

Discussions are typically organised into '*threads*' where one person starts a new discussion by posting an initial message asking a question, describing a problem or talking about an experience that they want to share, and other members post replies to that message. Members might then post additional messages in response to these replies, thus building up a hierarchical thread of messages that stem from the original posting (Cummings et al., 2002; Petrovčič, Vehovar, & Žiberna, 2012). The structure of these threads and messages is discussed more fully in Section 3.1.6.

2.3.3 Potential advantages of engaging with online support communities

There are many advantages to engaging with online support communities and receiving social support over the Internet (Finfgeld, 2000; White & Dorman, 2001), some of which appear to arise because of the computer-mediated nature of these communities (Coulson & Knibb, 2007).

2.3.3.1 Personalised access

It is easy for individuals to personalise how they use online support communities. Members can '*lurk*' until they feel ready to join in, they can choose when to log-off, and they can easily ignore discussions that do not relate to them (Colvin, Chenoweth, Bold, & Harding, 2004).

2.3.3.2 Access support at any time

Online support communities can be accessed twenty-four hours per day, seven days per week, making it possible for members to potentially obtain support at any time of the day or night (Malik & Coulson, 2008a). This introduces a high level of convenience and flexibility by enabling members to access support at times that are convenient to the individual, which may be particularly beneficial to those with work, family or study commitments (Coulson, 2013; Coulson & Knibb, 2007). In contrast, face-to-face support groups are only available during the set times when the group is scheduled to meet and they cannot provide a quick response if a crisis occurs (Galegher, Sproull, & Kiesler, 1998).

Being able to access support at any time may be of particular benefit to individuals with CRPS. For example, it means that individuals can directly access support as-and-when they need it, such as when their symptoms are bad or if they are having difficulty coping at that moment, while also giving them the flexibility of choosing not to use the community at times when they do not feel up to it.

2.3.3.3 Asynchronous communication

The asynchronous nature of discussion forums, Usenet newsgroups and some other types of online support community mean that there is no pressure or commitment to engage in real-time communication with other members (Coulson & Knibb, 2007). Instead, individuals can take their time to read messages and reflect upon their feelings while

considering if and how to reply, allowing members to control their level of involvement in a way that is not possible with traditional face-to-face communication (Malik & Coulson, 2008a). The removal of any time pressure to respond may help members to provide better quality replies, and also give them the opportunity to research other sources of help before responding to messages (Braithwaite, Waldron, & Finn, 1999).

2.3.3.4 Connect from anywhere

Each individual member can log in to an online support community from almost any location where they have access to a computing device with an Internet connection (Finfgeld, 2000). Unlike with traditional face-to-face support groups, this means there is no need to travel to a medical facility or other community venue where a support group is located. Individuals living with visual impairment, mobility problems or socially stigmatised conditions may find it difficult to overcome the geographical barriers associated with travelling to support groups (Braithwaite et al., 1999; White & Dorman, 2001). Similarly, individuals who live in rural areas or who have rare illnesses may need to travel long distances to attend support group meetings. The flexibility of being able to access online support communities from any suitable Internet-enabled location removes many of these barriers to access (White & Dorman, 2001).

Individuals with CRPS might not know anybody else in their local area that has the same condition, so this universal access may make it possible for individuals to interact with like-minded people where it might not otherwise be possible. It may also help individuals who are socially withdrawn and feel uncomfortable in face-to-face settings, as discussed in Section 1.2.5.4.

2.3.3.5 Anonymity

Socio-demographic factors like race, age, gender, educational level, occupation and social class can be hidden and are not readily obvious unless members voluntarily choose to

disclose them, and the disfiguring effects of certain diseases or treatment regimens can also be avoided (Finfgeld, 2000). This makes it easier for members to interact on a level-footing where individuals are judged purely on the basis of what they contribute to the community, instead of being judged according to preconceptions about how they look or what health condition they are living with.

The anonymity of online support communities may increase members level of honesty, intimacy and self-disclosure (White & Dorman, 2001), making it possible for individuals to vent and express their true feelings instead of maintaining a socially-desirable façade that they are coping with the illness (Rodham et al., 2009). It can help individuals to ask questions or discuss issues that they might not otherwise be able to talk about, because they might not feel comfortable discussing them with a doctor (Ravert, Hancock, & Ingersoll, 2004) and it might cause upset if raised with family and friends (Malik & Coulson, 2008b). However, the lack of privacy within online support communities could mean that members have to '*screen*' what they say when talking about some sensitive topics such as conflicts with family members (Colvin et al., 2004), and there is a possibility that some members might feel vulnerable and exposed after posting highly personal information that they would not normally disclose (Winzelberg, 1997).

2.3.3.6 Sensitive topics

The anonymous nature of the Internet, discussed in Section 2.3.3.5, may make it easier for individuals to discuss sensitive or embarrassing topics (Buchanan & Coulson, 2007; Coulson & Knibb, 2007). Face-to-face support groups have expectation of confidentiality, but they are not anonymous so attending them carries a potential risk of encountering somebody who is known to the individual and could publically expose their condition (Galegher et al., 1998).

Being able to discuss sensitive issues may also be of benefit to individuals with CRPS. The unpleasant and debilitating nature of the symptoms associated with this illness could potentially make individuals feel uncomfortable discussing their difficulties with family or friends who might not understand what they are going through.

2.3.3.7 Group composition

In principle there is no limit to the number of individuals who can join an online support community, and individuals who have Internet access can potentially join from anywhere in the world (White & Dorman, 2001). This means online support communities may be more heterogeneous than face-to-face support groups (Buchanan & Coulson, 2007; Coulson & Knibb, 2007), which could greatly increase the number of people that an individual interacts with and expose them to a wider and more diverse range of opinions than would otherwise be possible (Colvin et al., 2004). It can expose members to differing views about their problems, provide access to many different sources of advice that may help them to develop new and more effective coping strategies, and also help individuals to feel less isolated and alone in their experiences (Coulson & Knibb, 2007).

2.3.4 Therapeutic benefits of online support communities

The growing popularity of online support communities indicates that members may potentially experience a range of therapeutic benefits from engaging with them.

2.3.4.1 Personal relationships

Participating in online support communities may help to reduce the strain on relationships with partners, family and friends. In particular, individuals may use these communities to vent their frustrations by interacting with others who have been through similar difficulties without worrying loved one who might feel distressed or find it difficult to relate to their concerns (Attard & Coulson, 2012; Malik & Coulson, 2008b; Rodham et al., 2009). It can also reduce feelings of isolation by increasing the number of contacts

that an individual interacts with (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008) and helping individuals to recognise that they are not alone in their experiences (Coulson, 2013; Malik & Coulson, 2008a).

2.3.4.2 Empowerment

Empowerment is difficult to define but generally refers to having a sense of power or control; personal empowerment benefits the individual, group empowerment arises from the mutual benefits of shared knowledge, and community empowerment arises from the social and political activities of the group (Roberts, 1999). Online support communities can boost empowerment through processes like sharing information, obtaining emotional support, and finding recognition and understanding. This can empower members in several ways. Being better informed helps them to know more about their illness and make better decisions. They may feel more confident when interacting with healthcare professionals, prepare for appointments, and feel more comfortable asking questions or discussing treatment options. They may find it easier to accept the disease, feel more confident divulging their illness to others in their social environment, have increased optimism about the future after hearing about the positive experiences of others, and enhanced self-esteem (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008).

2.3.4.3 Relevance of social ties

How individuals benefit from online social support may be influenced by the strength of real-world social ties. Stronger social ties are associated with relationships with family and close friends, whereas weaker social ties are linked to colleagues and online support community members. Individuals without social ties, perhaps because they have no social network, a dysfunctional network, or a condition that makes it difficult for them to obtain support due to having a rare, unseen or stigmatised illness, benefit from the weak ties that come with online support community membership (Cummings et al., 2002). However,

one of the advantages of online support is that it can supplement support that is received from other sources (White & Dorman, 2001). Individuals with strong social ties may derive greater benefits from online social support and be more likely to help others if real-life family and friends also join the online support group, which helps to integrate their online and real-world support networks (Cummings et al., 2002).

2.3.5 Potential disadvantages of engaging with online support communities

Historically, there were concerns that online support communities might be addictive and could lead to increased social isolation by acting as a substitute for face-to-face relationships (Finfgeld, 2000; White & Dorman, 2001). While these concerns appear to be broadly unfounded (Malik & Coulson, 2010b; van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008), there are other more subtle potential problems associated with online support communities.

2.3.5.1 Access requirements

In order to participate in online support communities it is essential for individuals to have access to a computer, tablet, smartphone or some other device with an Internet connection. Internet usage statistics show that overall only 42.4% of the world population are Internet users (Internet World Stats, 2015), so only a minority of people have potential access to these online communities. Even in countries that have high levels of Internet use like the UK, Internet user typologies indicate that the majority of the population can still be categorised as either non- or occasional-users of the Internet (Brandtzæg et al., 2011; Selwyn et al., 2005), which again indicates that only a minority of people can use these communities. Furthermore, it is also essential to know how to use a computer, to understand whichever language the online support community uses, and to have adequate literary skills to read and write messages. Despite the potential worldwide membership of

online support communities, these barriers mean that only a small proportion of the world population are likely to use them.

2.3.5.2 Technical difficulties

Sometimes members experience technical difficulties while using online support communities. In particular they might find it difficult to join by registering an account with an online support community, have problems logging into their account, or find it difficult to use the online support community from other devices like their mobile phone (Malik & Coulson, 2010b).

2.3.5.3 Time consuming

Some online support communities have a large and active group membership where many people read messages and post replies every day. This can produce a high volume of messages, making it time consuming for an individual to read messages and compose replies (Malik & Coulson, 2010b; White & Dorman, 2001). Individuals who have family, work or other commitments may sometimes find it difficult to make time to read all the messages (e.g. Drentea & Moren-Cross, 2005), and using an online community may sometimes occupy time that could have been spent doing other things (Malik & Coulson, 2010b). The time commitment given to online communities illustrates the value of these discussions to members (McCarty, 1992).

2.3.5.4 Delays receiving replies

Some medical conditions like Parkinson's disease may make it difficult for members to actively participate in online support communities because of the nature of their symptoms, which could cause members to disappear unexpectedly or produce long delays between posting a message and receiving a reply (Attard & Coulson, 2012). After posting a message to ask a question or seek advice, there could be a delay before receiving a reply

and some messages do not receive any replies at all (Coulson, 2013; Malik & Coulson, 2010b).

2.3.5.5 Information overload

Information overload is defined as "*the experience of feeling burdened by large amounts of information received at a rate too high to be processed efficiently or used effectively*" (Misra & Stokols, 2012, p. 739). The high volume of messages in some online support communities can diminish the value of those communities, especially for newly joined individuals who may feel confused and overwhelmed while looking for information (Mo & Coulson, 2014). Additionally, it may be difficult to find relevant information by searching through message archives to examine previous answers that have been posted (Coulson, 2013). Members may respond to information overload by only replying to simple messages, by posting simpler replies or by withdrawing from active participation in the community (Jones, Ravid, & Rafaeli, 2004).

2.3.5.6 Absence of social cues

Social cues like facial expressions, body language and tone of voice are not present within online support communities, which can sometimes present difficulties (Coulson & Knibb, 2007). This can lead to misunderstandings if individuals misinterpret what others have said, or produce feelings of awkwardness if people make incorrect assumptions about other members (Attard & Coulson, 2012). Members often include smiley-face emoticons or excessive punctuation in their messages as a substitute for these missing social cues (van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008).

2.3.5.7 Lack of physical proximity to others

The lack of physical proximity on the Internet can make it difficult to develop a meaningful face-to-face relationship with other members, and also makes it impossible to offer physical affection like touching, holding hands, or giving the other person a hug

(Coulson, 2013; Malik & Coulson, 2010b). Additionally, members sometimes report that they feel isolated and alone in their real lives after logging off from their computer (Coulson, 2013).

2.3.5.8 Antisocial behaviour

Many online support communities are '*open*' and allow anyone to read messages or anonymously register a username so they can post replies (see Section 3.1.5.2). This could potentially lead to antisocial behaviour where some individuals harass others or behave in ways that disrupt the community (Burnett, 2000). The fear of receiving aggressive or inappropriate replies is one of the reasons why some members become '*lurkers*' who read messages without posting replies of their own (Preece, Nonnecke, & Andrews, 2004). Despite these concerns, research indicates that the postings in online support communities are overwhelmingly positive with very few instances of negative or abusive messages (Malik & Coulson, 2010a, 2011; van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008).

2.3.5.9 Misleading advice

Some members of online support communities have expressed concerns that the relative anonymity of the Internet can make it difficult to judge the accuracy and trustworthiness of information (Coulson & Knibb, 2007). For example, there is a possibility that some messages might be posted by '*imposters*' who pretend to have a particular health condition when they are really employees of a drug company or some other organisation with a vested interest in wanting to promote a particular treatment (Coulson, 2013).

When a member posts a reply offering information or advice, others will often join in to share their own opinions and these responses may help the individual to assess the credibility of the initial posting (Malik & Coulson, 2011). Messages containing inaccurate or misleading information may be more common in communities with low levels of

activity (Hwang et al., 2007), but overall it appears that the incidence of misleading information is low. For example, in a study by Esquivel, Meric-Bernstam, and Bernstam (2006) it was reported that only 0.22% of postings contain misleading information, and inaccuracies were corrected by other members within an average time of just over four-and-a-half hours. Hence, it appears that fears about the possibility of exposure to misleading or dangerous information may be unfounded (van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008).

2.3.5.10 Overrepresentation of negative experiences

Members may post more messages when their symptoms are particularly bad, and stop posting when they feel better. This can be demoralising, especially if few positive messages or success stories get posted. Reading '*horror stories*' about other people's negative experiences can produce feelings of concern or anxiety, especially if the member learns about problems or complications that they were not previously aware of, or worries about the same thing happening to them in the future (Coulson, 2013; Holbrey & Coulson, 2013; Malik & Coulson, 2010b).

2.3.5.11 Feeling like an outsider

Some members can find it difficult to '*fit in*' with online support communities, particularly if existing members have cliques and strong bonds. Attempts to join in and engage with others are not always reciprocated, and may lead to individuals receiving unhelpful responses or no response at all (Holbrey & Coulson, 2013; Malik & Coulson, 2010b).

2.3.6 Usage information

This section will consider how people discover online support communities, their reasons for joining, the socio-demographic and medical profile of users, and areas where further research is needed.

2.3.6.1 How people discover online support communities

Most individuals discover online support communities in one of three ways: by chance while looking for health information on the Internet; by hearing about them from other people such as professionals, patient organisations and family members, or by direct marketing by active members of the online support community (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008).

2.3.6.2 Reasons for joining

People join online support communities for a variety of reasons including wanting to obtain or exchange social support (38.2% of respondents), obtaining information and sharing insights with others (38.2%) and for friendship (17.1%) (Ridings & Gefen, 2004). Other reasons for joining are reflected in the benefits of community membership, such as being able to access support at any time, to alleviate feelings of isolation, and to use the community as a vehicle through which individuals can discuss coping strategies and feel better about themselves (Coulson & Knibb, 2007).

2.3.6.3 Socio-demographic and medical profile of users

It appears that individuals who use online support communities are broadly similar to those who use the Internet for other health-related purposes (Mo & Coulson, 2010b). Online support community use is associated with being better educated, having a higher income, using complimentary or alternative therapies, and having a worse health status (Owen et al., 2010).

Individuals with certain health conditions like depression, anxiety, stroke, diabetes, cancer or arthritis are more likely to use online support communities (Owen et al., 2010), and online support community use may be higher among people with rare, stigmatised or socially isolating illnesses because those conditions make it harder to obtain support within the local community (White & Dorman, 2001).

It appears that 54% of online support community users have never used a face-to-face support group (Owen et al., 2010), suggesting that online support helps people to obtain support that might otherwise be inaccessible or difficult to obtain (White & Dorman, 2001). Barriers to using online support communities include difficulty finding a suitable group, having to write about and discuss health problems online, and needing to sit at a computer for long periods of time (van Uden-Kraan et al., 2011).

2.3.6.4 Relevance to CRPS

With the exception of two studies conducted by Rodham and colleagues (Rodham, Gavin, Coulson, Watts, & Heath, 2013; Rodham et al., 2009), which are discussed in Section 2.3.7 and Chapter 5, little is known about how individuals with CRPS use online support communities. Additionally, research into online support communities is usually conducted using a cross-sectional approach that only captures a snapshot in time, which does not adequately capture the dynamic and constantly evolving nature of online communities (Malinen, 2015). Longitudinal studies are needed to fully understand how members use and benefit from these communities.

2.3.7 What people talk about

Many studies have investigated what members talk about within online support communities (e.g. Attard & Coulson, 2012; Finn, 1999; Malik & Coulson, 2008b; Ravert et al., 2004; Rodham et al., 2009). Across a range of health conditions, studies have highlighted a number of recurring topics that frequently arise within these communities.

In addition to talking about symptoms, treatment, side-effects, coping strategies, the impact of chronic illness on everyday activities, and their hopes and fears for the future, a number of other topics emerge. First, members emphasise the importance of being able to communicate with others who can understand them and have been through similar experiences (Malik & Coulson, 2008b; Ravert et al., 2004). Second, they stress the

importance of having a safe environment where they can vent and express their true feelings without the risk of hurting others or damaging social relationships (Attard & Coulson, 2012; Malik & Coulson, 2008b; Rodham et al., 2009). Third, they express frustration at public misconceptions that can make it difficult for family and friends to truly understand what it is like to live with an illness (Malik & Coulson, 2008b; Rodham et al., 2009). Fourth, they talk about how the information, social support and advice shared within these communities can have a profound impact on members, helping them to feel less alone and develop more effective coping strategies to overcome the issues unique to each illness (Attard & Coulson, 2012; Rodham et al., 2009).

In the context of CRPS, a limited amount of research has investigated what individuals talk about. Rodham et al. (2009) examined messages posted by adults in a CRPS community and identified the following four themes: '*Focussing on the positive*' emphasised what individuals can still do despite the limitations of their CPRS, instead of dwelling on things they cannot do. '*Venting*' was concerned with using the community as a safe environment in which to express their frustrations and true feelings without upsetting loved ones. '*Support*' focussed on the importance of providing support as well as receiving it. '*The hospital as a cure*' expressed their hope that medical professionals might be able to offer them a cure, and the disappointment of having to learn how to self-manage the condition.

2.3.8 Levels of engagement

Historically, it was thought that there are two main levels of interaction within online support communities: '*active participation*' and '*lurking*' (Burnett, 2000; Preece et al., 2004; Tanis et al., 2011). Active participants read messages that have been written by other community members and contribute to the discussions by posting replies of their own, to provide support and share their knowledge and experiences with other members.

In contrast, '*lurking*' is a form of non-interactive behaviour where individuals browse through the group reading messages without posting replies.

In their review, Amichai-Hamburger et al. (2016) identified three major determinants or '*lurking*' behaviour within online communities: individual differences, social-group processes, and technological setting. Individual differences refer to personal characteristics and intentions that influence participation, and comprise need gratification (posting or '*lurking*' to fulfil their needs), personality (different personality traits require different motivations to post), time availability (posting may be too time-consuming), and self-efficacy (confidence using the online community). Social-group processes refer to characteristics of the online community, and comprise socialization (adapting to the online community), type of community ('*lurking*' is less common in health communities than other types of forum), social loafing (feeling that their contributions may be inconsequential), responses to '*delurking*' (how newcomers are treated), and quality of response (replies to their first message influence the likelihood of posting again). Technological setting refers to external characteristics, and comprises technical design flaws (user interface that works and is easy to use), and privacy and safety (how personal information is used and who can read messages).

'*Lurking*' can sometimes have negative connotations because it is associated with free-riding and benefitting from the contributions of others without contributing anything yourself (Tanis et al., 2011). However, research indicates that 86.8% of '*lurkers*' start out with good intentions to contribute to the online community but find themselves deterred from taking part for a complex variety of reasons including not feeling the need to contribute, wanting to learn more about the community before posting messages, feeling that they do not have anything worthwhile to offer, not being able to post messages because of technical problems like not being able to make the software work, and

disliking certain aspects of the community because they feel shy, are worried about receiving aggressive responses, or are concerned about how new members are treated (Preece et al., 2004).

'*Lurkers*' are thought to make up the majority of online community membership (Burnett, 2000). While '*lurking*' might be an effective strategy for obtaining information or distracting yourself from a stressful situation without needing to disclose yourself to the group, it appears that individuals who actively contribute to online support communities derive greater benefits from community membership (Tanis et al., 2011).

There are two theories that might explain why active participation is important. First, actively posting messages should make it easier to find people to talk to, as well as speeding up the process of obtaining the required information and support to help them deal with a problem. Second, the act of writing a message might itself have a beneficial effect on coping because it involves needing to construct an understandable account of what they are experiencing, which might lead the individual to have a clearer understanding of the problem or prompt better ways of coping with it (Tanis et al., 2011). Research indicates that '*lurkers*' tend to be older than active participants, they spend less time using online support communities, and they receive less social support and less useful information (Mo & Coulson, 2010a).

According to Burnett and Bonnici (2003), behaviour within online communities is influenced by explicit and implicit norms. Social norms define the attitudes and behaviours that are considered to be acceptable for members of an online community, and can vary from one community to another. Explicit norms refer to rules that are outlined in formal documents like Frequently Asked Questions (FAQs) that explain the purpose of the community and what standards of behaviour are expected from members. Implicit norms are not formally outlined and can only be learned and understood by observing the

day-to-day interactions of established members. Newly joined members are sometimes advised to '*lurk*' in a community before actively joining in so they can learn the implicit rules and avoid sanctions or expulsion from the group for violating those norms. Core members of the community appear to play an important role in this process because they are defining members who reinforce community norms.

Participation in online communities may be more complex than a simple dichotomy between posters and '*lurkers*'. It is unclear how frequently an individual needs to post messages for them to be regarded as being an active participant, or how much time needs to pass without posting any further messages for them to be viewed as a '*lurker*'. Members may switch between period of active contribution and periods of reading messages without contributing, and both of these are legitimate types of participation (Malinen, 2015).

2.4 Theoretical approaches

Online social support has been studied from a range of theoretical perspectives. This section will consider some of the current theories, with particular attention to social support as a theoretical approach because social support underpins some other theoretical perspectives that will be discussed such as optimal matching theory.

Social support, LaCoursiere's theory of online social support, optimal matching theory, the uses and gratifications model, and the helper-therapy principle will all be examined. The results from Chapters 5, 6 and 7 will be considered in light of these theories.

2.4.1 Social support

2.4.1.1 Definitions of social support

The study of online support communities is linked to theories of both social support and computer-mediated communication (Wright & Bell, 2003). Social support has been

studied in so many ways and from so many perspectives that it has become surprisingly difficult to define, with some definitions being circular or lacking in conceptual clarity (Hutchison, 1999; O'Reilly, 1988). This has important research implications because a clear definition is fundamental to operationalizing social support so that it can be measured in a valid and appropriate way (O'Reilly, 1988).

Definitions of social support range from the broad, for example, "*the resources provided by other persons*" (Cohen & Syme, 1985, p. 4) through to definitions that describe the processes of support, such as, "*social support is conceived to be information belonging to one or more of the following three classes: 1. Information leading the subject to believe that he is cared for and loved. 2. Information leading the subject to believe that he is esteemed and valued. 3. Information leading the subject to believe that he belongs to a network of communication and mutual obligation.*" (Cobb, 1976, p. 300).

Generally, social support has been defined in the literature in terms of providing help and protection to others, particularly to individuals (Langford, Bowsher, Maloney, & Lillis, 1997). It is possible that there could be two distinct types of social support: everyday support that promotes a general sense of well-being, and crisis support that people can draw upon during critical times (O'Reilly, 1988). It is also important to distinguish between social support and social networks, because these are sometimes confused in the literature (Hutchison, 1999; O'Reilly, 1988). Social support refers to the help that people receive while social networks provide a framework through which support can be received.

Social networks vary on a number of dimensions including size (number of people), homogeneity (how similar they are to each other), frequency of contact (how often they interact), duration (how long they have known each other) and reciprocity (the extent to which interactions are reciprocal) (Berkman, Glass, Brissette, & Seeman, 2000).

2.4.1.2 Relationship to health

A large body of literature has examined the relationship between social support and health, indicating that social support is associated with numerous health benefits including improved treatment adherence across a range of illnesses (DiMatteo, 2004), improved cardiovascular, neuroendocrine and immune system functioning (Uchino, 2006), and reduced mortality among older adults (Penninx, van Tilburg, Kriegsman, et al., 1997). Research has highlighted the important role of social support in various medical conditions including arthritis (Penninx, van Tilburg, Deeg, et al., 1997), breast cancer (Nausheen, Gidron, Peveler, & Moss-Morris, 2009), coronary atherosclerosis (Wang, Mittleman, & Orth-Gomer, 2005), diabetes (van Dam et al., 2005) and depression (Marroquín, 2011).

There are multiple pathways through which social networks can affect health and well-being (Berkman et al., 2000). Upstream forces such as cultural norms, discrimination, poverty, political culture and war all influence the type of social network that an individual has access to. Social networks provide access to various kinds of social support including emotional and instrumental support, they expose individuals to social influences such as peer pressure, they help to reinforce bonding and social roles, and they also provide access to resources such as jobs, housing and medical care. Finally, these all have a health impact by influencing behaviours such as smoking, alcohol intake and adherence to medical treatment, they influence psychological mechanisms such as self-efficacy and coping strategies, and they can also affect physiological processes including immune system functioning, cardiopulmonary fitness and the transmission of infectious diseases.

2.4.1.3 Social support theories

Two influential theories that propose to explain how social support produces health benefits are the buffering model and main-effect model (Cohen & Wills, 1985). The buffering model suggests that social support has a buffering effect that helps to protect individuals from the effects of stress, while the main-effect model proposes that social support is directly beneficial to health regardless of how much stress an individual is experiencing. There is support in the literature for both of these models (Callaghan & Morrissey, 1993; Penninx, van Tilburg, Deeg, et al., 1997; Spitzer, Bar-Tal, & Golander, 1995).

2.4.2 LaCoursiere's theory of online social support

LaCoursiere (2001) outlined a theory of online social support that is divided into four sections, comprising initiating events, mediating factors, online social support, and outcomes.

First, individuals are triggered to seek online social support following an *initiating event*, such as a change in their health status or a change in their perceived health. Some health conditions are acute (e.g. pain following surgery) whereas others are chronic (e.g. CRPS that has failed to resolve itself), and either of these can cause changes in perceived health together with potential disruption to that person's lifestyle.

Second, these initiating events are influenced by *mediating factors*, which influence the need to seek online support. There are four categories of mediating factor: health factors (e.g. the individual's health status, what condition they have been diagnosed with, the medications they are taking, and how it has affected their quality of life); demographic factors (e.g. age, gender, marital status, socio-economic status, cultural background); perceived individual factors (e.g. stress levels, coping ability, social isolation, whether

they have feelings of helplessness or uncertainty) and Internet use factors (e.g. have they used the Internet before, and are they comfortable using it for health-related purposes).

Third, the initiating events combined with mediating factors influence support-seeking behaviour, with *online social support* occurring through three filters: the perceptual filter (the individual's emotional state influences their receptiveness to support and the level of benefit gained from seeking support), cognitive filter (the intellectual processing of support, such as seeking information about a medical procedure) and transactional filter (an evaluation of the support received, to assess how relevant it is to the individual).

Fourth, the *outcomes* of accessing and taking part in online social support can be classified in three ways: support mediation, information processing, and evaluative functions. The first two outcomes, support mediation and information processing, are quantitative outcomes that produce measurable changes in perceived health, stress levels, coping ability and quality of life. The third outcome, evaluative functions, is a qualitative outcome that occurs on the Internet as a result of the individual's interactions within the online support community, and relates to the number of messages posted, the content of those messages, and the conversational exchanges that took place between members.

While this theory provides a clear definition of social support and integrates many different perspectives to develop a wider understanding of online support community use, unfortunately some of the concepts are poorly defined and explained. For example, it lists support mediation and information processing as quantitative outcomes of using online support, but there is no clear explanation of what these terms mean and what they refer to. LaCoursiere (2001)'s concept of initiating events is discussed further in Chapter 5, where it is examined as a component of how individuals engaged with the Bath CRPS forum.

2.4.3 Optimal matching theory

Optimal matching theory (Cutrona & Suhr, 1994) falls within the buffering model of social support that was discussed in Section 2.4.1.3 (Cohen & Wills, 1985) and proposes that certain types of social support will be more helpful depending on what kind of problem an individual is experiencing. For example, offering to go grocery shopping may provide practical help to someone with a broken leg, but it will not provide the comfort and support that a person needs if they are upset following the death of a loved one. Hence, for social support to be effective, the type of support that is being offered needs to '*optimally match*' the needs of the recipient.

The Social Support Behaviour Code (Cutrona & Suhr, 1992, 1994) identifies five main types of social support: informational support (factual information, offering advice and providing feedback); emotional support (expressing concern, showing that you care, and empathising and sympathising with the situation); esteem support (complimenting their skills and abilities, and reassuring them of their value as a person); network support (providing a sense of membership and belonging), and tangible aid (practical assistance like supplying items they need or performing a service for them). Optimal matching theory divides these categories of social support into two groups: action-facilitating support and nurturant support.

Action-facilitating support helps 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 helps people to cope 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 well-being, empathising with their situation, offering to be there, and reminding them that they are not alone in their experiences. Nurturant support benefits the individual by helping them 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 et al. (1999) reported that emotional support was important in online support for disabilities, where individuals 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 individuals to overcome problems and 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, and emotional support helped with uncontrollable problems such as those relating to diagnosis and treatment.

Optimal matching theory is discussed further in Chapter 6, where it is used to explain the pattern of social support that was present in the Bath CRPS forum.

2.4.4 Uses and gratifications model

The uses and gratifications model says that people use media to gratify their needs and desires (Lee & Hawkins, 2010), or to put it another way, they have motives for using media like the Internet and they expect to achieve particular outcomes from doing this (Grace-Farfaglia, Dekkers, Sundararajan, Peters, & Park, 2006).

As Ruggiero (2000) explains, this model has a long history dating back to the 1920s, with early studies investigating cinema viewing, radio broadcasts and newspaper reading in an attempt to understand why people engage with mass media. The growing popularity of the Internet was of particular interest to researchers of this model because the Internet differs from other mass media outlets in three important ways: interactivity (the Internet blurs the line between broadcaster and receiver); demassification (the Internet lets people select content that is of interest to them), and asynchronicity (people can access content at a time of their own choice, when it is most convenient to them). This gives Internet users a much greater level of control than what is available with other mass media outlets, which Ruggiero says creates a wide range of communication behaviours for uses and gratifications researchers to examine.

Online support communities have been examined using the uses and gratifications model. For example, individuals who have unmet informational needs or emotional support needs have been found to spend a greater amount of time seeking information or emotional support than those whose needs are being met by their existing resources (Lee & Hawkins, 2010). Additionally, individuals use online support communities because they are motivated by wanting to seek information, to help others, to meet others in similar circumstances, for relaxation, and to maintain offline relationships (Chung, 2013).

The uses and gratifications model is briefly mentioned in Chapter 6.

2.4.5 Helper-therapy principle

The helper-therapy principle (Riessman, 1997) describes how the act of helping other people can itself have a beneficial effect upon the individual. Riessman (1997) outlined ten principles that play an important role in this process:

1. *The peer principle-social homogeneity*: Social homogeneity means that people who share the same condition can understand and relate to each other's feelings and experiences in a way that others cannot. The peer principle means that individuals are influenced more strongly by peers who they perceive as being similar to themselves. Thus, being helped by somebody who is similar to you and has been through the same experiences has a powerful impact upon the individual.
2. *Self-determination and new forms of participation*: The individuals within the self-help setting collectively determine what kind of help will be provided and what form it will take. This means that the self-help process is self-governing, where everybody contributes without any external control or governance.
3. *Helper therapy and the restructuring of help*: Helping others is the best way of being helped. The help receiver also provides help to others, which helps them to feel good about themselves, reduces their dependency on others, and assists them to develop their own skills and abilities.
4. *The consumer as producer and consumer capital*: An individual might give help at one time and receive help at another time, or both give and receive help simultaneously. For example, simply having good coping skills will allow the individual to help themselves, which frees resources for other things, and at the same time they will be helping others by demonstrating those coping skills.

5. *Strength vs. pathology*: Self-help settings are built on the inner strengths of the individuals within that group. Everybody has something to give, and those strengths form the basis of that person's helper role. This stops people from dwelling on pathologies (i.e. they no longer act based upon their problems and deficiencies).
6. *Non-commodification*: Self-help is free and reciprocal, not a commodity to be sold for profit.
7. *Social support*: Self-help relationships provide one of the many types of social support that acts as a buffer to protect people against the negative effects of stress, and can also help people to appraise their situation in a more productive way.
8. *Ethos*: Self-help settings are associated with their own ethos, which is usually founded on sharing, informality and participation. Sometimes this can have a wider helping effect, like the AA steps that involve making amends to people who the individual has previously hurt.
9. *The self-help solution*: Self-help is based on experiential learning. Individuals are not stigmatized for seeking help, nor are they helped by experts. Instead help is provided by people with the same condition, based on their own struggles, successes and experiences.
10. *Internality*: The beliefs of people with a health condition can be very different to the political or social perception of that illness, so help is based on internal factors like self-determination, resilience, and healing from within rather than seeking an external cure administered by somebody else.

These principles dramatically reduce the number of people seeking help while drastically increasing how many people are available to provide help, and they also give individuals a socially important role as a help provider instead of the low social status that is

sometimes associated with being a help recipient (Riessman, 1997). Unfortunately, Riessman (1997) does not cite any references for his ten principles, which makes it difficult to assess how much evidence there is to support each principle. It is also unclear whether all ten principles are considered equally important to the helper-therapy process or if there is a hierarchy where some principles are more important than others.

Although the helper-therapy principle has been applied to online support communities, these ten principles are rarely examined in online studies. Instead the theory is used as a general explanation for how individuals benefit from helping others. For example, research indicates that the helper-therapy principle leads to improved self-esteem among online support community members (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008), with individuals benefiting from adopting valued social roles, and receiving feedback on their attempts to overcome the challenges and difficulties associated with living with a chronic illness (Mo & Coulson, 2012). Wanting to help others can also be a reason for setting up and moderating online support communities (Coulson & Shaw, 2013).

The helper-therapy principle is briefly mentioned in Chapter 7.

2.5 Summary

The Internet is the most widely used computer network in the world and plays an important role in a wide range of daily activities including online shopping, staying in contact with family and friends, and seeking information, advice and support for health-related problems. Health-related Internet use involves a range of activities including searching for information, interacting with healthcare professionals and using online support communities.

Online support communities are a type of virtual community dedicated to discussing health-related issues, where individuals can interact with other people who have had similar difficulties and experiences to obtain information, support and advice. Researchers have examined the potential advantages and disadvantages of engaging with online support communities, who uses them, what people talk about, and level of engagement. Many theoretical approaches have been used to study online support communities including social support, optimal matching theory, and the helper-therapy principle.

Chapter 3: Conducting online research with discussion forums

Abstract

This chapter will examine practical and ethical issues related to conducting message analysis studies in discussion forums and online support communities. It looks at reasons for studying forums, the advantages and disadvantages of forum studies, how to identify a suitable forum for analysis, data sampling, and quantitative and qualitative methods of analysis. There are numerous ethical issues associated with message analysis studies, so the second part of this chapter will consider the distinction between public and private places on the Internet. This includes if and how informed consent should be obtained, difficulties surrounding confidentiality and anonymity, if it is possible to debrief participants, and deception.

3.1 Discussion forums

3.1.1 History of online support communities

Virtual communities have a long history on the Internet with Usenet newsgroups first appearing in 1979, followed by bulletin boards in 1985 and World Wide Web discussion forums in the mid-1990s (Ridings & Gefen, 2004). Online support communities are a type of virtual community with a health-related focus, which provide an online environment where individuals can interact with other people who have had similar experiences to exchange social support, information and advice. Although online support communities can be based on several different technologies including Usenet newsgroups, e-mail ListServs and World Wide Web discussion forums (Robinson, 2001), discussion forums have become the most prevalent type of online support community (Barak et al., 2008). Discussions within these communities are typically organised into '*threads*' where one member starts a new discussion by posting an initial message asking

a question or describing an experience that they want to share, and others then post replies (Cummings et al., 2002; Petrovčič et al., 2012).

3.1.2 Reasons for analysing forums

Holtz, Kronberger, and Wagner (2012) explain that discussion forums can be linked to governmental, political or other organisations where the members know each other in real life, or they may be online communities where the members have never met and the group was created to allow like-minded individuals to discuss issues of shared interest. Forums produce huge quantities of naturalistic data in the form of conversations between members, with millions of postings organised into threads that make it easy for researchers to identify and select content that is relevant to the research question. These online discussions produce rich data as members respond to previous contributions by posting new and detailed information to clarify how they think and feel on various different issues, while the anonymity of the Internet may help members to express themselves more freely without the social constraints normally associated with face-to-face interaction. Forums may also be valuable for research into '*sensitive*' topics, where it might otherwise be difficult to recruit participants and obtain insights into socially undesirable activities and behaviours.

3.1.3 Advantages and disadvantages of online data collection

Forum members acknowledge the potential scientific importance of message analysis studies, and recognise that they can provide researchers with important insights into the needs, opinions and experiences of individuals living with a health condition (Bond, Ahmed, Hind, Thomas, & Hewitt-Taylor, 2013).

There are numerous advantages to forum studies compared with other research methodologies. Forums can be used to research individuals who might otherwise be difficult to contact, such as those living with a rare illness (Hennekam, 2011) or who have

not sought professional help for a health condition (Granello & Wheaton, 2004). Data can be collected without using a '*gatekeeper*' to access participants, although permission may still be needed from forum moderators if researchers need to post an announcement about a study to invite people to take part (Hamilton & Bowers, 2006). Studies may be cheaper to run and easier to administer compared with other methods of data collection (Hewson, Laurent, & Vogel, 1996).

There are also disadvantages to forum research, particularly in relation to representativeness. Participants might not be representative of any particular sample group because Internet access is not equally distributed across the population (Granello & Wheaton, 2004; Holtz et al., 2012), which means that some individuals are more likely than others to use the Internet and forums (Mo & Coulson, 2010b; Office for National Statistics, 2015b; Owen et al., 2010).

3.1.4 Finding a discussion forum

Researchers can conduct studies by analysing messages from one or more existing forums, or by creating a bespoke forum as part of the research project. Both of these options will now be examined.

3.1.4.1 Using existing forums

The strategies used by researchers to identify discussion forums that might be suitable as potential sources of data in research studies are broadly similar to those used by the members themselves. As discussed in Section 2.3.6.1, it appears that most members discover online support communities while searching for health-related information on the Internet, after hearing about them through others such as patient organisations or family members, or through direct marketing by the community (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008).

Researchers typically find forums by using an Internet search engine like Google to search for relevant keywords, such as '*online/internet support group*', '*forum*', '*message board*', '*discussion group*' and the name of a health condition like '*diabetes*', '*cancer*' or '*Parkinson's disease*' (Attard & Coulson, 2012; Coulson & Greenwood, 2012; Hwang et al., 2007; van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008). Additionally, researchers can ask colleagues and experts in the appropriate field for details of any online support communities that they might know about (van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008). This will produce a list of potential forums, each of which must be examined to assess whether it is suitable for analysis. The researcher needs to consider whether the topics that are discussed in each forum will inform the research question, if members are likely to be representative of the desired target population, and whether the forum contains enough postings by a sufficiently large number of members to provide an appropriate volume and depth of data for analysis (Holtz et al., 2012).

Other criteria that researchers have used to select appropriate forums include whether it is public or private (Eysenbach & Till, 2001), if group norms place restrictions on who is welcome to join (Eysenbach & Till, 2001), the popularity of the website in terms of visitors and page views (Hwang et al., 2010), and whether the forum has a long history or has won any awards (Coursaris & Liu, 2009). The willingness of moderators and website administrators to support research activities might also be a consideration (e.g. Mo & Coulson, 2010b; van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008). If other researchers have previously posted messages in the forum to recruit participants and received a hostile or negative response, then this may indicate that scientists are not welcome (Eysenbach & Till, 2001).

When selecting a forum as a data source it should be remembered that members will not normally be aware that their messages are being downloaded and analysed as part of a

scientific study, and they may react badly if they realise that the forum is being monitored and used for research purposes (Eysenbach & Till, 2001; Hudson & Bruckman, 2004). Forum members join and participate in online communities for a variety of personal reasons including looking for information, social support or friendship (Ridings & Gefen, 2004), and not because they want to act as '*guinea pigs*' who are being observed and studied by researchers (Eysenbach & Till, 2001). This leads to a range of ethical difficulties associated with the study of online communities, particularly relating to public and private places, informed consent and deception, which are discussed in Section 3.2. Researchers have a responsibility to ensure that no harm is done to individual members or the overall community that is being studied.

3.1.4.2 Creating a bespoke forum

An alternative approach is for researchers to create and launch their own dedicated forum as part of a research project (Armstrong, Koteyko, & Powell, 2012; Im & Chee, 2006; Sanders, Rogers, Gardner, & Kennedy, 2011; Zrebiec & Jacobson, 2001). This has ethical advantages over taking data from an existing forum because participants can be told when joining that the forum is part of a scientific study, so they can consent to their data being used for research purposes. However, creating a new forum may considerably increase the expenses involved in conducting a study. Server space will be needed to host the forum on the Internet, specialist computer skills are required to set-up and maintain a forum, and it may be difficult and time-consuming to recruit enough forum members for the community to become self-sustaining and generate the required amount of data for analysis.

3.1.5 Types of forum

In the literature, there are several ways of categorising and distinguishing between different types of forum.

3.1.5.1 Discussion topic

There are forums dedicated to discussing a diverse range of topics including pets, musical instruments, computer programming and fishing (Ridings & Gefen, 2004), wristwatches (Rothaermel & Sugiyama, 2001), and online support communities where members exchange support, information and advice relating to health and medical issues like cancer (Coulson & Greenwood, 2012), Complex Regional Pain Syndrome (Rodham et al., 2009), diabetes (Ravert et al., 2004), eating disorders (Eichhorn, 2008), Parkinson's disease (Attard & Coulson, 2012) and weight loss (Hwang et al., 2007).

3.1.5.2 Access type

Forums can be categorised as being open or closed (Eysenbach & Till, 2001; Robinson, 2001). *Open communities* are freely accessible, allowing anyone to read messages that have been posted by other members without first needing to register or obtain a password. However, it is often still necessary to register and create a username before being able to post messages and contribute to discussions. *Closed communities* are typically password protected so that they can only be accessed by people who are registered users. This means that members can view messages and post replies, but nobody else can access the community. Closed communities are almost always regarded as being private places on the Internet, whereas open communities could be public or private depending upon the nature of the community. This has important ethical implications that are discussed in Section 3.2.1.

3.1.5.3 Ownership

Forums can be member-initiated or organisation-sponsored (Porter, 2004). Member-initiated forums are created and run by individuals, and can be socially-oriented with a focus on hobbies and relationships or professionally-oriented with a focus on expert knowledge and shared professional interests. Organisation-sponsored forums are owned

and run by commercial businesses, non-profit organisations such as charities or patient groups, and government agencies.

3.1.5.4 Scope

Some forums like Diabetes UK <www.diabetes.org.uk> are dedicated to discussions about just one illness, while others like Health Boards <www.healthboards.com> have many different boards covering a wide range of health-related issues. Additionally, some websites are single function communities that provide a standalone forum without including any other resources, while others are comprehensive communities that include a range of additional resources in addition to the forum (Finfgeld, 2000).

3.1.6 Forum and message characteristics

Most forums have a hierarchical, tree-like structure. A forum can contain several distinct boards or sections that are arranged thematically, where each board will contain many different threads, and each thread will contain one or more individual messages written by members (Holtz et al., 2012). For illustrative screenshots, see Section 4.2.1.

At the top level, the forum usually has an index page listing the various boards or sections that are available. Each board provides an area where members can have a particular type of discussion. For example, the '*Diabetes.co.uk global diabetes community*' forum <www.diabetes.co.uk> has many separate boards including ones for introductions (for new members to introduce themselves to the group), newly diagnosed people (where individuals who have recently been diagnosed can share their experiences), Type 1 diabetes (discussions specifically about Type 1 diabetes), Type 2 diabetes (discussions specifically about Type 2 diabetes), parents (a section where the parents of diabetic children can obtain support), food and nutrition (to share recipes and talk about managing the illness through diet), and living with diabetes (advice about employers and claiming social security benefits).

Each of these boards will contain many different conversations, which are organised into groups of related messages called '*threads*'. A thread consists of an initial message where a member starts a new discussion by asking a question, describing an experience or requesting advice, and other members contribute by posting replies (Cummings et al., 2002). Some forums allow members to reply to an individual message, giving threads a complex structure where a reply might receive several further replies of its own. However, other forums are more limited and only allow members to post replies to the thread rather than responding to a specific message, making it more difficult to keep track of who members are replying to (Petrovčič et al., 2012). The use of threading makes it possible for forum members to take part in several discussions simultaneously, by posting replies in one thread and then moving to another thread or board to contribute to discussions on other topics and with other members.

Each forum posting contains a message together with header information about the member who wrote it, such as their username and the date and time when it was posted to the group (Petrovčič et al., 2012). The username is an alias that each member chooses when they register an account with the forum, and it may consist of their real name, a nickname, or a word or phrase that makes them anonymous. It is possible for more than one person to share an account, for example a husband and wife might share their password so they can both use the forum with the same username. Members will often '*sign*' their posting by writing their name or nickname at the bottom of the message, in a similar way to signing a letter, which helps to clarify who wrote the message. When an individual joins multiple forums, some people will choose different usernames for each forum to help maintain their anonymity.

Some forums may display additional information from that user's profile such as their age and gender, their geographical location, the date when they joined the forum, how many

messages they have posted, how many threads they have started, and possibly an avatar. An avatar is a small graphical image that is typically displayed alongside that member's username, showing their photograph or another picture that they have selected.

The message text may include quoted extracts from other messages that have previously been posted to the group, making it easier to clarify which parts of a message that person is responding to. It is often possible to embed pictures into the message, attach files, or include links to other webpages. Another key feature of many forums is the use of emoticons (Im & Chee, 2006; van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008). These are '*smiley faces*' included in the text to indicate the emotional state of that member, as a substitute for non-verbal cues like facial expressions and tone of voice that are missing from written communication. Two distinct styles of emoticon can be found within forums: Faces that are typed using normal keyboard characters like ':-)' and ':-(' (a colon, dash and parenthesis that resemble a happy or sad face when the page is rotated sideways), and graphical images depicting various facial expressions that are embedded into the text. Members may also include a signature line to their message. A signature is an additional line or two of text that is appended to the end of the posting, which may contain their name, a favourite quote, a link to their personal website or blog, or some other information that the user wishes to share with other members.

3.1.7 Sampling and data collection

Sampling in forums involves selecting which threads and/or messages to download for analysis. Two main sampling methods can be used (Holtz et al., 2012). First, the researcher can download all messages that were posted within a particular time period (e.g. Malik & Coulson, 2008b, 2011). Second, a random number generator can be used to choose which threads and messages to include, giving each message an equal chance of inclusion in the study (e.g. Attard & Coulson, 2012; Elwell, Grogan, & Coulson, 2011). It

is possible to combine both approaches by choosing a date range and then selecting random threads for analysis (e.g. Malik & Coulson, 2010a; Mo & Coulson, 2008). Alternatively, the researcher could analyse the complete set of all messages posted to the forum (e.g. Zrebiec & Jacobson, 2001), which might be useful with smaller forums or where a new forum has been launched as part of a research project.

The selected postings should be exported and stored in a text document such as a word processor file on the researcher's computer, in case the forum closes or becomes unavailable (Holtz et al., 2012). A major advantage of using online data from forums is that it eliminates the possibility of transcription errors. Forums use written communication that produces an automatic and error-free verbatim transcript of the interactions between members, rather than relying on a recording that needs to be subsequently transcribed in an attempt to capture as much detail as possible from the original interaction. However, the analysis of forum postings can be problematic. The process of importing messages into a word processor or other program may cause key features of the text to be lost, including emoticons and the position of line breaks (Im & Chee, 2006). This may be a particular problem with forum messages that use embedded graphical images for emoticons rather than emoticons that have been typed using standard keyboard characters.

The loss of some textual features might potentially threaten the credibility of the data because forums do not convey non-verbal cues like facial expressions and tone of voice, and textual features such as spacing and emoticons could provide some clues to the emotional state of participants and the context of what is being said (Im & Chee, 2006). The researcher needs to decide which aspects of the forum are important for analysis so that important features can be retained while irrelevant features are removed from the downloaded version of the text. For example, the unedited forum data is likely to include

the original formatting and tables used to display the messages on the webpage, together with usernames, emoticons, avatars, embedded pictures, quotes from previous messages, and any advertisements that might have originally been shown alongside the postings (Holtz et al., 2012).

Holtz et al. (2012) recommend removing tables and quotations, converting the messages into plain text, and replacing all hard returns with soft returns. Although it is possible to use a word processor's '*find and replace*' function to change personal details like names or usernames, care should be taken when doing this. Personal information can be located randomly throughout the text and it may be difficult to identify search terms that will replace all personal data without some details being overlooked like the names of doctors and family members (Kaiser, 2009).

The participants in forum studies are the members who wrote the messages selected for analysis. Unfortunately, the anonymity of the Internet can make it difficult to obtain demographic information about participants. Some members may include their age and gender in their profile (Holtz et al., 2012) and it is sometimes possible to obtain information about participants by examining the content of messages posted to the forum (Coulson et al., 2007; Malik & Coulson, 2010a). It is difficult to confirm the accuracy of demographic information about participants (Holtz et al., 2012), but one study comparing profile data with self-reported information from online interviews found that the demographic information in online profiles was broadly accurate, with gender discrepancies only arising in 5.9% of participants and age discrepancies in 11.2% of participants (Stieger & Göritz, 2006).

In qualitative analysis, theoretical saturation occurs when patterns in the data become repetitive, no new themes emerge, and all categories are well defined. Normally the researcher uses probing questions and real-time interaction to achieve data saturation.

Forum data uses asynchronous communication where members participate according to their own schedule, they may visit the site infrequently, and some members may only post a minimal number of messages to the group. This makes it difficult to achieve saturation when using forum data, unless the data is supplemented through synchronous communication such as interviews (Im & Chee, 2006).

3.1.8 Data analysis

Message analysis studies typically take a phenomenological approach and involve studying activities and behaviours that are unique to the Internet, such as how people use online communities and what they talk about (Skitka & Sargis, 2006).

3.1.8.1 Quantitative analysis

Data can be analysed using both quantitative and qualitative methods. Quantitative analysis has been used to examine the word count of forum postings, how many replies each message receives, and whether messages are posted during the daytime, evening or at night (Winzelberg, 1997). Other studies have assessed the quality of advice provided by members (Hwang et al., 2007), and investigated how long it takes for other members to identify and correct any inaccurate information posted to the group (Esquivel et al., 2006).

3.1.8.2 Qualitative analysis

Qualitative analysis is commonly used to study the content of messages and investigate what people talk about. This can involve using text-reducing or text-enhancing methods (Holtz et al., 2012). Text-reducing methods like content and thematic analysis reduce the complexity of qualitative data by identifying key themes or categories, while text-enhancing methods like discourse analysis provide a more detailed analysis that looks at the meaning of different styles of communication.

3.1.8.3 Content analysis

Content analysis (Elo & Kyngäs, 2008; Pfeil & Zaphiris, 2010) is used to code rich textual data into categories, which can then be used to produce simple statistics summarising the data by counting how many occurrences there are in each category. Several factors must be considered before performing content analysis. First, the researcher must decide whether to use deductive or inductive coding. Deductive coding uses a top-down approach that involves categorising the data into a pre-determined set of categories, which can be useful for testing an existing theory or comparing different data sources. Inductive coding takes a bottom-up approach that entails deriving a new set of categories from the data as part of the coding process, and can be useful for developing new theories. Second, an appropriate unit of analysis must be chosen. Data can be categorised on the level of individual sentences, paragraphs, whole messages, or complete threads of messages. Smaller units like sentences may produce large volumes of data that are very time consuming to analyse, while larger units like whole threads could take such a broad overview of the data that some of the finer details are lost. Third, an individual unit of data may contain more than one meaning, so the coding categories can be either mutually-inclusive or exclusive. Inclusive coding allows each unit to be coded into more than one category, while mutually-exclusive categories mean that the data can only be assigned to one category that most closely reflects its meaning. Content analysis is commonly used when researching online support communities, for example to investigate the social support content of messages using deductive coding (e.g. Coulson et al., 2007; Mo & Coulson, 2008) and inductive coding (e.g. Hwang et al., 2010).

3.1.8.4 Thematic analysis

Thematic analysis (Braun & Clarke, 2006) is used to identify patterns (or "*themes*") that are present across a data set, to describe, analyse and interpret a phenomenon of interest.

Thematic analysis is not linked to any particular theoretical approach, and several issues need to be considered before analysing the data. First, the researcher must consider what constitutes a theme. Themes need to capture an important element of the phenomena being investigated, and the researcher needs to use personal judgement to decide how frequently the phenomena should occur within the data before it can be regarded as being a theme. Second, deciding what kind of analysis to perform. The researcher can identify themes that reflect and summarise the entire data set, but where some of the depth of analysis is lost because of the breadth of material covered. This can be useful for investigating new areas where little is known about participant experiences. Alternatively, the researcher can focus on themes relating to a specific area or research question, providing greater depth of analysis on a narrower part of the data set. Third, deciding whether to use inductive or deductive coding. Inductive coding involves identifying themes directly from the data without any attempt to fit in with existing frameworks or preconceptions. Deductive coding is similar to deductive content analysis, where the data is coded into an existing framework but without counting the number of occurrences. Deductive thematic analysis has been used to investigate the social support content of messages in online support communities (e.g. Coulson & Greenwood, 2012) and inductive thematic analysis has been used to investigate what people discuss within these communities (e.g. Attard & Coulson, 2012; Malik & Coulson, 2008b).

3.1.8.5 Discourse analysis

Discourse analysis (Willig, 2003; Yardley & Murray, 2004) is a text-enhancing method that takes a fundamentally different approach to qualitative analysis. With discourse analysis, language is used to construct social meanings rather than reflecting what people think. For example, the statement '*I am in pain*' might be used as a reason to withdraw from a social setting, to avoid completing a task at work, or to get sympathy from family

and friends (see Yardley & Murray, 2004). There are a number of approaches to discourse analysis including discursive psychology and Foucauldian discourse analysis. Discursive psychology is used to analyse transcripts of naturally occurring conversations to see how people manage accountability. Foucauldian discourse analysis can be applied to any stimuli that carries a symbolic meaning and goes beyond discursive psychology to investigate the relationship between discourse, feelings and behaviour (Willig, 2003). Discourse analysis has been used with online data to investigate the use of rhetorical devices in racist jokes posted on websites (Weaver, 2011), and to see how community identity shaped subsequent discussions in an online support community for type-1 diabetes (Armstrong et al., 2012).

3.2 Ethical issues

The British Psychological Society's code of ethics highlights four key principles for conducting research with human participants (British Psychological Society, 2009), which require special consideration when conducting research on the Internet (British Psychological Society, 2013).

First, respect for the autonomy and dignity of persons: Researchers must respect the knowledge and experience of potential participants. In particular, individuals have the right to know what a study is about so they can freely decide whether to take part, they should not be subjected to procedures that might cause a long-term impairment of their autonomy, and their privacy and confidentiality should be protected. Second, scientific value: The study should have clear aims, make a legitimate contribution to scientific knowledge, and be conducted in a way that ensures the integrity of the findings. Third, social responsibility: Researchers need to be aware of their personal and professional responsibilities when conducting a study, and consider the possible consequences that may arise as a result. Fourth, maximising benefits and minimising harm: During all stages

of the research process, researchers should maximise the benefits of their work while minimising the risk to participants and being sensitive to any impact that may arise from taking part. When conducting message analysis studies, these principles have implications for the distinction between public and private places, informed consent, confidentiality, anonymity, debriefing and deception. Each of these will now be considered in more detail.

3.2.1 Public and private places

The distinction between public (openly accessible) and private (walled off) sources of data has important implications for researchers (Eysenbach & Till, 2001; Robinson, 2001). As discussed in Section 3.1.5.2, some online support communities ('*open*' communities) are freely accessible so that anybody can read messages, while others ('*closed*' communities) are password-protected and can only be accessed by registered members. Determining whether a community perceives itself as being public or private can be complicated (Roberts, 2015). When messages are posted in open communities, some members may believe their postings are private without realising that they can be freely read by anybody who chooses to access them (see Lomborg, 2013). Password-protected communities are usually private, groups with a smaller number of members are more likely to be private than those with a larger membership base, and groups intended for a specific target audience such as children may also be private (Eysenbach & Till, 2001). Legal regulations can influence whether online behaviour is public or private, for example some countries might define e-mails or other types of electronic communication as '*protected communication*' (Kraut et al., 2004). To determine if a community is public or private, researchers should consider whether it is openly accessible, how it is perceived by members, the sensitivity of discussions, and the intended audience (Roberts, 2015).

Whether an online support community is public or private has implications for informed consent (Section 3.2.2) and deception (Section 3.2.6).

3.2.2 Informed consent

Informed consent involves ensuring that participants are aware of the purpose of the study, what kind of data will be collected, how the data will be used, what potential benefits might arise from the research and what risks are involved, making sure they have the opportunity to withdraw from the study at any time and have their data destroyed on request, and obtaining documented proof that the participant has understood this information and agreed to take part prior to commencing with the study (British Psychological Society, 2011).

There are mixed opinions among online support community members regarding whether informed consent is needed for message analysis studies: some members are happy for their messages to be used in research without their knowledge or permission, while others want researchers to obtain informed consent before using their data (Bond et al., 2013). However, there are numerous challenges with obtaining informed consent for this type of research. Some individuals might be impossible to contact if they are no longer active within that community (Roberts, 2015), and individuals may react badly if permission is requested to use their messages in research (Eysenbach & Till, 2001; Hudson & Bruckman, 2004). Consent requests may produce feelings of resentment or distrust within communities, they can disrupt the very conversations that the researcher hoped to study, and if an individual responds by leaving the community then it may prevent that person from obtaining the help they needed.

Researchers have a responsibility to avoid harming individual members and the online support community. When collecting data from public communities, it may be appropriate to waive the need for informed consent because the risks involved with

obtaining consent can be greater than the protection it offers, but consent should always be obtained when collecting data from private communities (Robinson, 2001).

3.2.3 Confidentiality

Researchers have an ethical duty to keep data about participants or collected from participants confidential. This means that data should not be disclosed to anyone who is not directly involved with the study, and if the results are published then participants can expect that any data relating to them should be anonymous so they cannot be identified (British Psychological Society, 2011).

Confidentiality protocols typically mean that all data relating to a study should be securely stored, and personally identifiable data should be stored separately to anonymous research data (British Psychological Society, 2011). Ensuring confidentiality poses a number of difficulties when conducting online research because of how the Internet works, which may make absolute confidentiality impossible (British Psychological Society, 2007).

In particular, using e-mail to discuss research or share data with collaborators could breach confidentiality. First, e-mails pass unencrypted through multiple servers before they are delivered to the intended recipient, and can potentially be viewed by others in a similar way to sending information on the back of a postcard (Kreindler, 2008). Second, e-mails containing sensitive information could be accidentally sent or forwarded to unintended recipients (Granberry, 2007). Third, some employers monitor the computer use of employees, ranging from monitoring e-mails through to tracking individual keystrokes as they are typed on a computer keyboard (Friedman & Reed, 2007). Any of these could lead to information being accidentally or unknowingly disclosed to third parties and hence violate the confidentiality of participants.

3.2.4 Anonymity

Whereas confidentiality involves managing private information, anonymity refers to obscuring or removing potentially identifiable information about participants and research sites, and can be a useful tool for maintaining confidentiality (Tilley & Woodthorpe, 2011).

In message analysis studies, the biggest threat to anonymity comes from disseminating the results (van den Hoonaard, 2003). Researchers typically include quoted extracts from messages as evidence for their findings (e.g. Attard & Coulson, 2012; Malik & Coulson, 2008b), and various approaches have been used to attribute these quotes. Quotes can be reported anonymously without identifying either the participant or online support community they were taken from, participants can be given pseudonyms, or quotes can be attributed to the participants' real identity (Roberts, 2015). If data is taken from an '*open*' community then the use of quotes could threaten the anonymity of participants. It is often possible to use a search engine like Google to trace quotes back to the person who wrote it, compromising their anonymity regardless of whether or not a pseudonym has been used (Eysenbach & Till, 2001; Kraut et al., 2004).

Consequently, researchers should check all quotes using a search engine to make sure they cannot be traced, or take alternative steps to protect participants' anonymity by paraphrasing quotes or using composite accounts that convey the intended meaning of multiple messages without directly quoting them (Roberts, 2015). Researchers should also avoid reporting any distinctive or personally-identifiable information that could potentially lead to participants being recognised from their descriptions using deductive disclosure (Kaiser, 2009; van den Hoonaard, 2003).

3.2.5 Debriefing

The British Psychological Society advises researchers to debrief participants as soon as possible after they have taken part in a study. This allows the researcher to explain about the nature of the study, particularly if it involves deception or withholding information. It gives researchers the opportunity to assess whether participants have experienced any unforeseen harm, so that appropriate assistance can be provided. The debriefing procedure might also include steps to return participants to a positive mood if the experimental procedure involves putting them in a negative state of mind (British Psychological Society, 2009, 2011).

Debriefing participants in message analysis studies involves many of the same challenges and difficulties as obtaining informed consent (see Section 3.2.2). If a study has been conducted without the knowledge or consent of participants, then those individuals will not be aware that their data has been used for research purposes and hence they cannot be debriefed afterwards.

Kraut et al. (2004) recommend that participants should be debriefed if deception is used during data collection, but there is a risk of harming participants by doing this. If a researcher joins an online support community under false pretences to collect data that would otherwise be impossible to access (e.g. Brotsky & Giles, 2007), then debriefing participants to explain the deception is likely to produce feelings of anger and betrayal. Notifying the members of an online support community that a researcher has been collecting data under false pretences could lead to increased suspicions and an erosion of trust among members. The potential harm to individuals and the community may be greater than the protection that debriefing is intended to provide, and hence it is often necessary to waive debriefing when conducting this kind of research.

3.2.6 Deception

The concept of deception can be difficult to define. Withholding information from participants is not normally regarded as a form of deception, instead deception refers to deliberately and explicitly providing misleading or erroneous information to participants – in effect, lying to them (Hertwig & Ortmann, 2008). Deception violates a participant's ability to give informed consent to taking part in research because an individual cannot consent if they have been misled about the study and any risks that might be involved in taking part (Sell, 2008). Consequently, deception should only be used under exceptional circumstances where it is necessary for the integrity of the study (British Psychological Society, 2009).

Normally, observational studies require the consent of the people being observed unless the research is conducted in a public place where individuals would expect to be observed by strangers (British Psychological Society, 2011). However, as discussed in Section 3.2.1, it is uncertain whether the Internet should be regarded as a public or private place. There are concerns that researchers who join an online support community in order to collect data without the knowledge of other members may be engaged in a form of deception (British Psychological Society, 2007). Message analysis only involves deception under very specific circumstances where the researcher knowingly misrepresents him or herself by posing as an individual with a health condition in order to join a group under false pretences (e.g. Brotsky & Giles, 2007).

3.3 Summary

Virtual communities have a long history on the Internet, with discussion forums emerging in the mid-1990s. There are many reasons for studying forums, and members recognise the potential scientific importance of this type of research. Most forums have a hierarchical tree-like structure comprising boards, discussion threads and individual

messages, where sampling involves selecting which threads/messages to download for quantitative and/or qualitative analysis. There are serious ethical dilemmas associated with analysing forum messages. It is unclear whether the Internet should be treated as a public or private place. Some studies are conducted without obtaining informed consent or debriefing participants, because the risks involved with obtaining consent may be greater than the protection it offers. Confidentiality and anonymity are difficult to protect, and deception occurs if a researcher joins a forum under false pretences to collect data.

Chapter 4: Research context and questions

4.1 Bath CRPS project

This thesis used data that was collected for a research project titled '*Meeting the support needs of patients with Complex Regional Pain Syndrome (CRPS) through innovative use of wiki technology*', which for brevity will be referred to as the Bath CRPS project.

The Bath CRPS project was developed by four researchers, Dr Jeff Gavin, Professor Karen Rodham and Dr Leon Watts from the University of Bath, and Dr Neil Coulson from the University of Nottingham. It was funded by the Health Services and Delivery Researcher (HS & DR) programme, part of the National Institute for Health Research (NIHR), as project number 10/2000/40.

Its aim was to investigate how the Internet can be used to support the needs of individuals living with Complex Regional Pain Syndrome. Specifically, a World Wide Web discussion forum was created to examine what kind of support individuals receive by participating in forums, and then a collaborative wiki writing task was introduced to further study the development of social processes in psychological support. This took place over three phases: Phase 1 was launching the forum, which took place in June 2012. Phase 2 commenced three months later, when members were invited to participate in the collaborative wiki writing task that ran alongside the forum. This involved creating a webpage about CRPS similar to the one found in the Wikipedia online encyclopaedia, but written from the viewpoint of individuals with CRPS to address misconceptions about the illness. Phase 3 made the wiki page available to participants and their family, friends and carers, to obtain their written qualitative feedback.

Three research questions were investigated by the Bath CRPS project. First, what constitutes support in newly developed online interactions? Second, how does the process

of giving and receiving support online evolve? Third, can the combination of an online forum and a collaborative writing task increase support relative to an online forum alone?

Their first research question was assessed by conducting an inductive thematic analysis of all introductory messages which led to the identification of five themes: journey to diagnosis, treatment, contact with health care professionals, looking for the positive, and hobbies. This was published as Rodham, Gavin, Coulson, et al. (2013), and will be discussed more fully in Chapter 5. Chapter 5 focusses on how individuals engage with forums, and builds upon their findings by arguing that introductory messages are just one part of a wider concept of engagement.

Their second research question used deductive content analysis to look at how many messages requested support, and what kinds of social support were present in messages. Chapter 6 also examines the support content of messages, but extends this further by looking at how support processes get started when a new forum is launched and how the support received might contribute to the CRPS '*four pillars of intervention*'.

Their third research question looked at the collaborative wiki writing task. Unfortunately, their analysis for this part of the project was limited because participants did not engage with the task in the way that was originally envisaged. Instead of discussing among themselves what information to include, participants were reluctant to openly share their thoughts. The participants who engaged with the task either added their suggestions directly to the wiki document or e-mailed the research team with their ideas. The collaborative writing task does not form part of this thesis so it will not be examined further. For a detailed overview of all aspects of the Bath CRPS project and its findings, see Gavin, Rodham, Coulson, and Watts (2014).

The research team recognised that the data collected as part of the Bath CRPS project, especially the content of forum messages, could be analysed to investigate a wider range of issues in addition to those posed by the project's original research questions. In order to make the best possible use of data and also maximize the potential benefits to individuals living with CRPS, all four members of the research team graciously gave permission to use and analyse the messages posted in their forum as the basis for this thesis.

4.2 CRPS forum

This section will describe the forum that was created as part of the Bath CRPS project, to explain what kind of forum was used, how long it ran for, the boards that were available, how many messages were posted on the forum, and also how forum members were recruited into the project.

4.2.1 Forum type

A forum was created and launched so that participants could post messages, read replies, take part in discussions, and exchange information, advice and social support. As discussed in Section 3.1.5.2, forums vary according to access type. '*Open*' forums are freely accessible, and provide full and unrestricted access to their message archives. This means that anybody can visit the forum, read messages and search through archives of previous discussions. There is no requirement for individuals to register a username and password unless they want to take part in discussions by posting messages of their own. '*Closed*' forums have access restrictions and are typically password protected. This ensures that the forum can only be used by individuals who have joined the group by registering with a username and password, making it impossible for anybody else to read messages and see what topics are being discussed.

The Bath CRPS project used a '*closed*' forum. This created a high degree of privacy for participants by creating an environment where participants could openly talk about their experiences and emotions without anybody other than the research team accessing and viewing their online conversations, and ensured that non-members would not be able to read messages without their knowledge or permission. All participants gave informed consent so that their messages can be read and used for research purposes. This was achieved by notifying potential participants that the forum was part of a research project before they registered as members. Additionally, the forum's welcome page reminded participants that "*all the text on this site will be stored for the purposes of the research we are carrying out. However, we shall anonymise this information such that you will not be identifiable in any reports or presentations we, as researchers, may make as a result of the project*". This avoided the ethical difficulties discussed in Section 3.2.2 associated with if and how to obtain consent when conducting message analysis studies.

Like most forums (see Section 3.1.6), the CRPS forum had an index page listing several boards that were arranged thematically according to discussion topic. Each board contained various discussion threads relating to that topic, and each thread contained all the messages and replies that were posted as part of that discussion. Threads were structured to append new replies to the end of the thread rather than attaching replies directly to individual messages. This gave threads a relatively simple structure that avoided the complexities of replies hierarchically receiving further replies of their own. Figure 1 shows a screenshot of the forum index page and figure 2 shows a screenshot of discussion threads in the '*Your thoughts and experiences*' board, both displayed using the Google Chrome Web browser to illustrate how the forum was presented to participants.

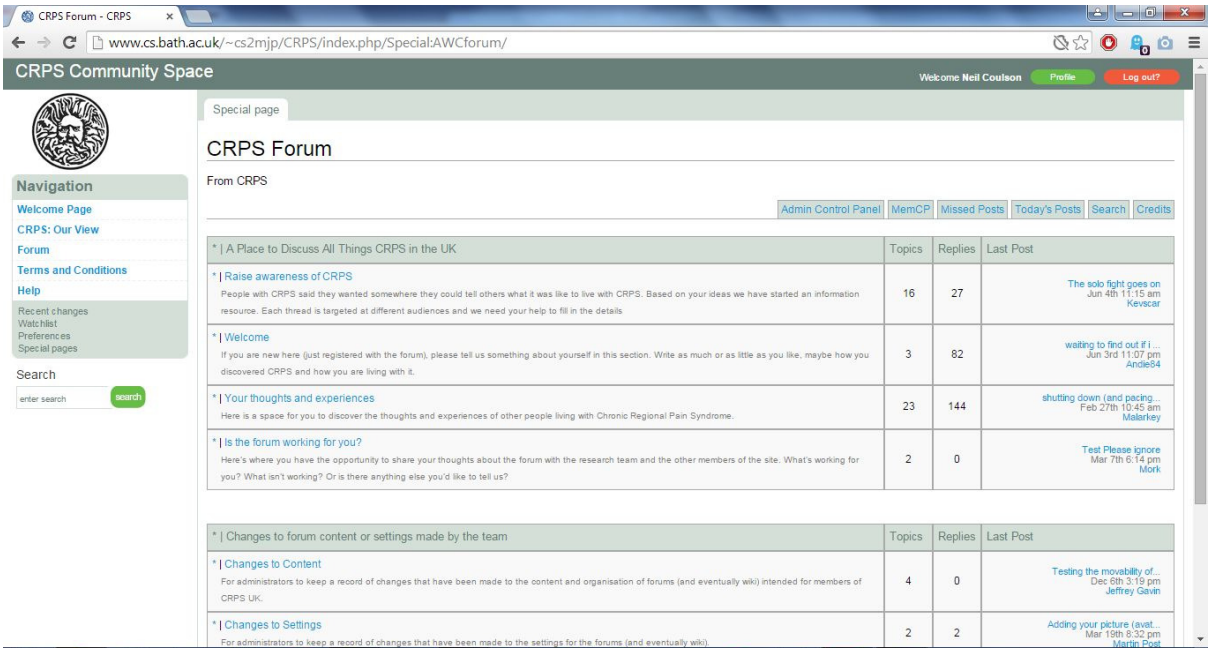


Figure 1: Screenshot of the forum index page.

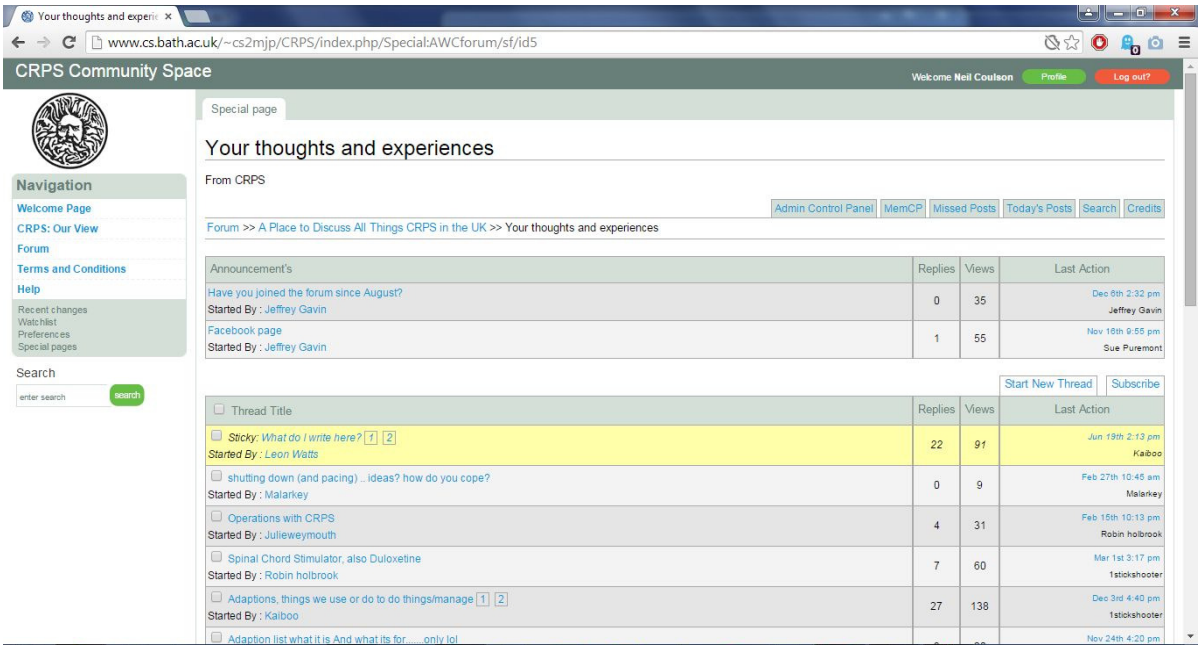


Figure 2: Screenshot of discussion threads in the '*Your thoughts and experiences*' board.

4.2.2 Duration

Originally the forum was intended to run for one year, from 1-Jun-2012 until 31-May-2013. Participants were notified that the forum would only be available for a limited duration and they were offered the opportunity to continue running the forum themselves after they project had ended, but they chose not to do this.

Unfortunately the forum was hacked midway through the planned duration of the project, making the data from the latter half of this period unusable. The hacking took place about seven months into the project, sometime around the end of 2012 or beginning of 2013, and was carried out by an unknown individual who bypassed the security checks on the registration page and created around 40-50 fake user accounts. The forum had to be temporarily closed for around six days to repair the damage, and it took a further month to clean up the site. Sadly the forum was severely disrupted by these events and did not regain momentum afterwards, highlighting the fragility of online support communities and how new forums can erode as quickly as they evolve.

These events made it necessary to identify a cut-off date for the studies conducted as part of this thesis, to separate the usable and unusable data. The cut-off date was decided by examining dates when the number of real members was known. This provided a choice of three dates: 8-Nov-2012 (49 members), 31-Dec-2012 (60 members) or 6-Jan-2013 (62 members). It was decided to use 31-Dec-2012 as the end date for the study because this had the smallest impact on the dataset. First, this date fell on the last day of the month and hence provided seven months of data for analysis. Second, it did not truncate any messages from discussion threads, leaving all conversation threads fully intact. Third, it meant that only two threads comprising a total of eleven messages were lost from the dataset. Despite the hacking incident, messages posted before this date were known to be legitimate and provided an accurate reflection of participant discussions.

Consequently, for this thesis, the forum was treated as having run for seven months from 1-Jun-2012 until 31-Dec-2012. This is comparable to allowing one month for new members to register, introduce themselves and learn how to use the forum, followed by a further six months during which they could take part in discussions and use the forum in any way they found helpful.

4.2.3 Boards and messages

The forum initially consisted of three boards, each dedicated to discussions about different aspects of CRPS and the wider research project. A fourth board, '*Raise awareness of CRPS*', was later added for discussions about the collaborative wiki writing task mentioned in Section 4.1; the wiki task does not form part of this thesis. Table 1 shows the board names and how they were described on the forum.

Two of these boards were researcher-led, and the other two were member-led. The two researcher-led boards were named '*Raise awareness of CRPS*' and '*Is the forum working for you?*'. These boards only contained a small number of threads and messages, and discussions within them were primarily initiated by members of the research team. The

Table 1: Forum board names and descriptions.

Name	*Description*
Raise awareness of CRPS	People with CRPS said they wanted somewhere they could tell others what it was like to live with CRPS. Based on your ideas we have started an information resource. Each thread is targeted at different audiences and we need your help to fill in the details
Welcome	If you are new here (just registered with the forum), please tell us something about yourself in this section. Write as much or as little as you like, maybe how you discovered CRPS and how you are living with it.
Your thoughts and experiences	Here is a space for you to discover the thoughts and experiences of other people living with Chronic Regional Pain Syndrome.
Is the forum working for you?	Here's where you have the opportunity to share your thoughts about the forum with the research team and the other members of the site. What's working for you? What isn't working? Or is there anything else you'd like to tell us?

member-led boards were named '*Welcome*' and '*Your thoughts and experiences*'. These contained a larger number of threads and messages, and discussions were primarily initiated by participants.

The dataset for this thesis consisted of all the threads and messages that were posted in the two member-led boards, because discussions on these boards reflected the thoughts, feelings, concerns, opinions and experiences of individuals living with CRPS. A small number of messages were removed from the dataset, excluding them from the analysis. First, there were three double-posted messages in the '*Welcome*' board, where the same message had been accidentally posted twice in the forum creating an unintended duplicate of the original posting. These unplanned duplicates were removed from the dataset. Second, a thread consisting of one message was accidentally created in the '*Your thoughts and experiences*' board and then deleted by the original author, so this too was excluded. This left 76 messages (2 threads) from the '*Welcome*' board and 145 messages (17 threads) from the '*Your thoughts and experiences*' board, forming an overall total of 221 messages.

To prepare these messages for analysis, an offline copy of the messages was created by using the computer's copy-and-paste function to transfer each posting from the Web browser window into a word processor document, where the messages were converted into plain text format (see Section 3.1.7). This removed tables and other formatting features from the forum, while retaining textual features like spacing, punctuation and the use of abbreviations. Unfortunately, embedded graphical images like emoticons were lost as part of the conversion into plain text.

4.2.4 Participants

Participants were initially recruited to join the Bath CRPS project through an announcement sent to members of crps@themin, a UK support group formed by

individuals with CRPS, inviting their members to take part. Interested individuals were invited to contact a member of the research team, who responded to prospective participants by sending them a welcome e-mail with further information about the project and a link to the forum. Later, additional participants were recruited from CRPS-UK (an off-shoot of crps@themin, which had become defunct by then) by posting an announcement on their website, Facebook group and Twitter feed.

All participants lived in the UK apart from one former UK resident who was now living in New Zealand. Despite the potential worldwide reach of the Internet, the project focussed on a predominantly UK-based sample because the findings were targeted towards the NHS and UK CRPS treatment settings.

As described in Section 4.2.2, the forum had a total of 60 registered members at the time of the cut-off date on 31-Dec-2012. This consisted of 23 individuals who were diagnosed with CRPS and actively posted messages on the forum (38.3% of all registered users), two administrators involved in running the forum (3.3%), and 35 '*lurkers*' who read messages written by other people without posting any messages of their own (58.3%).

Demographic information about the 23 active participants was limited because of the anonymous nature of the Internet, however some information was collated by looking at the content of their messages. Gender was available for all participants, with 5 males (21.7%) and 18 females (78.3%). Age was available for 9 participants, and ranged 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, and ranged from 5 months to 10 years with a mean duration of 3.9 (3.5) years.

The 23 individuals living with CRPS formed the participant sample for the empirical chapters in this thesis. Chapters 5 and 6 used all 23 participants while Chapter 7 only used

a subset of them. The participants used, and the reasons for this, will be fully described in the relevant chapters.

4.3 Research questions

The research conducted for this thesis has two broad aims. First, to examine the development of online support processes in relation to the launch of a new online support community. Second, to investigate the provision of social support for CRPS within an online support community. The following sections outline the rationale for each study and the specific research questions that were addressed.

4.3.1 Study 1: Engagement

Chapter 5 examines how individuals engage with forums. Existing studies have typically looked at engagement in a restricted context, such as making rudimentary distinctions between '*posters*' (i.e. individuals who post messages) and '*lurkers*' (i.e. individuals who only read messages) (Mo & Coulson, 2010a; Nonnecke & Preece, 2000; see also Malinen, 2015), with researchers focussing on established forums rather than newly launched forums. Little is known about engagement in newly launched forums, or particularly how individuals with CRPS engage with forums. Chapter 5 investigates engagement in the Bath CRPS forum with the following three aims:

(1) To identify the pattern of membership growth when a new online support community is launched;

(2) To investigate patterns of engagement through an analysis of message headers;

(3) To investigate how members introduce themselves to the group, the structure of these introductions, and what information they disclose about themselves.

4.3.2 Study 2: Social support

Chapter 6 investigates social support within forums. Individuals with CRPS can become socially isolated (Galer et al., 2000; McCabe & Blake, 2008; Rodham et al., 2009), and forums may increase their social network (Rodham et al., 2009) as well as providing access to support at any time (Malik & Coulson, 2008a). Previous research has used optimal matching theory (Section 2.4.3) to examine what kind of social support individuals receive by participating in forums across a range of illnesses (Braithwaite et al., 1999; Coulson, 2005; Coulson et al., 2007; Coulson & Greenwood, 2012; Eichhorn, 2008; Malik & Coulson, 2008a), but these studies have focussed on existing forums. Little is known about how support processes become established when a new forum is launched. There has been a lack of research into what kind of social support is present in CRPS forums, and no studies have examined how forums might contribute to the CRPS '*four pillars of intervention*' that represent the '*gold standard*' for illness management (Section 1.2.4.5). Chapter 6 investigates social support in the Bath CRPS forum with the following aims:

(1) To investigate how support processes become established when a new online support community is launched;

(2) To examine the support content of messages in the context of optimal matching theory;

(3) To investigate how social support received over the Internet contributes to the CRPS '*four pillars of intervention*'.

4.3.3 Study 3: Longitudinal research

Most forum studies have been conducted using a retrospective and cross-sectional approach (for a review of the methods used, see Chen, 2014). Individuals often use online

support communities for an extended period of time (Coulson, 2013; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009) and their experiences are unlikely to remain static, so there is an urgent need for longitudinal research (Chen, 2014). Forum members use written text to form impressions of each other, build relationships and convey their experiences (Walther, 1996), so a longitudinal linguistic analysis of the words used by members, the context in which words are used, and how word use changes over time, might provide an insight into support-providing behaviour and the number of replies received. Chapter 7 uses a new longitudinal technique to analyse forum messages using case studies, with the following aim:

(1) To longitudinally investigate the use of health words, self and other-oriented messages, positive and negative words, and the number of replies received using four case studies in the Bath CRPS forum.

Chapter 5: Study 1 – An examination of engagement within a newly-created CRPS online forum

Abstract

Several studies have investigated how individuals engage with discussion forums, with a small but growing body of research focussing on three aspects of engagement: the number of individuals who use a forum (membership growth); how they use it (header analysis[5]) and how they introduce themselves (introductory messages). Most studies have looked at established forums, and little is known about what happens when a new forum is launched. This study examines how individuals engaged with the Bath CRPS forum. Results showed that membership growth occurred in '*bursts*' that were closely linked to the promotional strategies used to increase awareness of the forum. Header analysis revealed that the forum was used at all times of the day, evening and night, with a focus on providing support as well as receiving it. Introductory messages took the form of '*disease stories*' with six themes: personal details; precipitating event; symptoms; treatment; living with CRPS, and reasons for joining. Implications and areas for future research are discussed.

5.1 Introduction and research aims

Chapter 1 discussed CRPS symptoms (Section 1.2.1), how the condition is treated (Section 1.2.4) and difficulties living with CRPS (Section 1.2.5). In particular, as discussed in Section 1.2.5.4, individuals with CRPS may find it difficult to participate in social and recreational activities (Galer et al., 2000), leaving them with a greatly reduced network through which they can obtain support (Rodham et al., 2009). Consequently, individuals with this illness may benefit from social support that is received over the

[5] Message headers provide additional information about each message, such as who wrote it and when it was written, which can be analysed to investigate how individuals use a forum (see Section 3.1.6).

Internet by participating in online support communities, which were discussed in Chapter 2.

5.1.1 Engagement with online support communities

Within the literature, how individuals engage with online support communities has typically been considered in a restricted context. For example, some researchers have looked at how often an individual accesses a community (van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008; Zrebiec & Jacobson, 2001) or the time spent online in the average session (Boberg et al., 1995; Gustafson, Bosworth, Hawkins, Boberg, & Bricker, 1992), while others have described engagement using arguably rudimentary terms such as '*posters*' (i.e. individuals who post messages) and '*lurkers*' (i.e. individuals who only read messages) (Mo & Coulson, 2010a; Nonnecke & Preece, 2000; see also Malinen, 2015). Although these are legitimate components of engagement, this thesis argues that engagement is a far broader concept that requires further elaboration within research studies. Indeed, there is a small but growing literature that has considered engagement from a range of alternative perspectives, such as membership growth (Iriberri & Leroy, 2009), the analysis of header information (Galegher et al., 1998; Winzelberg, 1997) and introductory messages (Barak et al., 2008; Galegher et al., 1998).

In addition, most research has focussed on engagement within established forums where long-standing members have developed mature relationships that strengthen the community through mutual feelings of closeness and trust (Drentea & Moren-Cross, 2005; Iriberri & Leroy, 2009; Pfeil & Zaphiris, 2010; Winzelberg, 1997). These forums have established norms, in that they reward individuals for their contributions in the form of feedback and social recognition, and their self-sustaining discussions can produce a large volume of messages (Iriberri & Leroy, 2009). However, much less is known about how individuals engage with newly launched forums, which means that little is known

about how online relationships are initially formed when a forum is launched, or how support processes become established. Moreover, despite the prevalence of CRPS (see Section 1.2.2) and the potential benefits of online social support (see Chapter 2), there has been little research investigating how individuals with this debilitating illness use and engage with forums (for exceptions, see Rodham, Gavin, Coulson, et al., 2013; Rodham et al., 2009). Therefore the present study attempts to address some of the aforementioned issues, and investigates engagement within the Bath CRPS forum. In particular, it considers engagement in terms of these three aspects: membership growth, header analysis, and introductory messages.

5.1.2 Membership growth

According to Iriberri and Leroy (2009), discussion forums and other types of online community have a lifecycle that evolves through five distinct stages: inception; creation; growth; maturity and death. Each stage is associated with a particular set of needs and characteristics that shape and influence the life of the community.

The first stage, *inception*, involves developing an idea for a new online community. This may arise from a desire for support or information, to meet new people, or for some other reason. Individuals need to consider what kind of community they would like to create, the purpose of the group, who the target audience will be, and what kind of rules will be needed to keep the group running smoothly. In the second stage, *creation*, decisions are made regarding the technological components that will be required to build and launch the community. In particular, individuals need to decide whether their community will be a discussion forum, e-mail ListServ or another type of online group, and what software platform to use. After launching the community, the third stage is *growth*. As new members join and the group becomes established, individuals will post messages to request information, provide support, enforce community etiquette, or '*lurk*' by reading

other people's messages without actively contributing. During the fourth stage, *maturity*, trust will develop among members and they will develop lasting relationships. Additional new members will continue to join and provide fresh topics for discussion, while existing members will either continue using the community or lose interest and leave. The final stage, *death*, occurs if there is a loss of interest that causes members to stop participating, and there is no longer enough high quality content to sustain discussions. Accordingly, the growth of a newly launched forum plays an important role in its subsequent success or failure. Forums need to achieve a '*critical mass*' of members who are interested in interacting with each other and can produce a sufficiently diverse range of messages for discussions to become self-sustaining (Jones et al., 2004; McCarty, 1992).

Little is known about the membership growth of newly launched forums. In particular, membership growth could take a number of different forms. For example, a forum might have linear growth where a consistent number of new members join each month, exponential growth where a snowball effect causes an ever-increasing number of members to join, or burst growth where some months have a large increase in members while other months have little or no increase. Few studies have examined growth patterns, so little is known about forum growth and the number of people who engage with forums after they have been launched. Consequently, the first research aim for this study is to identify the pattern of membership growth when a new online support community is launched.

5.1.3 Header analysis

Header analysis reveals information about how members use forums. As discussed in Section 3.1.6, forum messages consist of both header information and the message body (Petrovčič et al., 2012), and have a number of distinct features that can be useful to researchers. For example, the header provides a range of information including the

username of the individual who created that message, their avatar, the date and time when the message was posted to the group, and it might also include other details such as the date when they joined the forum, the number of new threads created by that individual, and the total number of messages they have posted (Holtz et al., 2012; Petrovčič et al., 2012). The message body contains the textual part of the message, and can be used to calculate additional information such as message length.

A range of statistical data has been examined in the literature including the number of messages posted in the forum each day, the number of replies received in each thread, how long it takes to receive a reply, the number of words or lines of text in each message, and the time of day when messages are posted in the forum (Boberg et al., 1995; Eichhorn, 2008; Galegher et al., 1998; Pfeil, Svangstu, Ang, & Zaphiris, 2011; Winzelberg, 1997).

To date there have been no studies analysing header information in CRPS discussion forums. This means that little is known about how individuals with CRPS use forums, what time of day they post messages, how many messages they write, how many replies they receive, or how long it takes to receive the first reply. Consequently, the second research aim for this study is to investigate patterns of engagement through an analysis of message headers.

5.1.4 Introductory messages

When an individual joins a forum, the first message they write can be crucially important for their future engagement within that group. Existing members may respond to an introductory message by being supportive and welcoming, or critical and off-putting, or by ignoring it completely, all of which can have a profound impact on the new member and the likelihood of them continuing to engage with the forum (Barak et al., 2008; Joyce & Kraut, 2006). Individuals may use their first post to talk about their medical history

(Armstrong et al., 2012), in effect telling their '*disease story*'. This helps the newly joined member to establish their legitimacy (why they have joined) and authority (why others should listen to them and reply to their messages) within the group (Galegher et al., 1998).

A small number of studies have looked at introductory messages while investigating other topics related to forums. For example, in their examination of self-help mechanisms in an online support community for infertility, Malik and Coulson (2010a) reported that expressions of universality, i.e. that the individual is not alone and others experience similar problems and difficulties, were often made in response to introductory messages from newly joined members who felt lonely, lost or confused. In a study investigating common reasons for '*lurking*' in online communities, Preece et al. (2004) suggested that one strategy for encouraging individuals to become active contributors is by inviting them to post an introductory message.

In a recent study conducted as part of the Bath CRPS project described in Chapter 4, Rodham, Gavin, Coulson, et al. (2013) looked at the role of introductory messages in establishing the Bath CRPS forum, and described five themes: journey to diagnosis; treatment; contact with health care professionals; looking for the positive, and hobbies. Their analysis used the same dataset as the present study but it only focussed on how identities are formed when a new forum is launched. In particular, Rodham, Gavin, Coulson, et al. (2013) found that the first introductory messages that were posted '*set the tone*' for how later members subsequently introduced themselves. The present study extends their findings by looking at the wider role played by introductory messages in how members engaged with the forum.

Despite the importance of introductory messages, surprisingly little is known about how newly joined members introduce themselves in forums, what kind of information they

disclose, or the structure of their '*disease stories*'. Consequently, the third research aim for this study is to investigate how members introduce themselves to the group, the structure of these introductions, and what information they disclose about themselves.

5.2 Methods

5.2.1 Data collection

The data for this study was collected as part of the Bath CRPS forum described in Chapter 4. This study used all 221 messages that were posted in the '*Welcome*' and '*Your thoughts and experiences*' boards, as outlined in Section 4.2.3.

5.2.2 Participants

The participants were all 23 active participants from the Bath CRPS forum, as described in Section 4.2.4.

5.2.3 Analysis

The initial data preparation was carried out as described in Section 4.2.3.

Membership growth was analysed by studying the date when each participant posted their first forum message. These dates were entered into a Microsoft Excel spreadsheet, which was used to calculate how many new members joined during each month of the study.

Header analysis was then conducted by entering the header information from each message into a Microsoft Excel spreadsheet. This provided information about the date and time that each message was written, the username of the individual who created it, and the number of messages in each thread. The number of messages posted per day, number of messages posted by each participant, number of threads created by each participant, and time of day when each message was written were calculated using the combined data from both the '*Welcome*' and '*Your thoughts and experiences*' boards. However, the number of replies received and duration of time to receive the first reply

could only be calculated for the '*Your thoughts and experiences*' board because the '*Welcome*' board only had two threads and the first message in one of these threads was posted three months before the forum was publically launched, creating an outlier that would have skewed the dataset.

Introductory messages were analysed using thematic analysis (Braun & Clarke, 2006) to identify recurring patterns (or themes) that are present in the first message posted by each participant. An inductive approach was used to identify themes directly from the dataset, instead of coding the data into an existing framework. Previous research has indicated that individuals may use their first message to talk about their medical history and explain why they have joined the forum (Armstrong et al., 2012), so the analysis focussed on identifying the structure and key features of these disease stories. Content analysis (Elo & Kyngäs, 2008; Pfeil & Zaphiris, 2010) was then used to count the number of occurrences within each theme. The data was coded in units of whole messages, making it possible to count the number of messages in each theme. Non-exclusive coding was used, so if more than one theme was present in a message then all themes were counted instead of only counting the predominant theme.

5.2.4 Ethical considerations

The Universities of Nottingham and Bath both granted ethical permission for this study, which was conducted in accordance with the British Psychological Society (2013)'s ethical guidelines for online research.

As described in Section 4.2.1, all participants consented to their data being used for research purposes when they joined the Bath CRPS project. Participant's anonymity and privacy were protected by removing usernames and other potentially identifying information from the quoted extracts of postings, to minimise the risk of deductive disclosure being used to identify participants from their descriptions (Kaiser, 2009; van

den Hoonaard, 2003). Furthermore, the Bath CRPS project used a closed, password-protected forum that makes it impossible to trace quotes back to their original source using an Internet search engine (Kraut et al., 2004), further protecting their privacy.

5.3 Results

5.3.1 Membership growth

Table 2 shows the number of new participants who joined the forum during each month of the study.

Table 2: Number of members who joined the forum each month.

Month	*New members*	*Cumulative total*
June	7	7
July	1	8
August	1	9
September	5	14
October	6	20
November	2	22
December	1	23

Forum membership grew in irregular '*bursts*'. The first burst occurred in June when an initial group of 7 participants joined the forum. This was followed by a second burst in September and October when an additional 11 participants joined. The other months of the study all experienced a consistent but much lower rate of background growth, with only one or two new members joining during each of these months.

5.3.2 Header analysis

5.3.2.1 Messages per day

The number of messages posted per day ranged from 0-13, with a mean of 1.0 (2.1) messages per day. The modal number of messages per day was 0, with 138 out of 213 days (64.8%) where no messages were posted.

5.3.2.2 Messages per participant

The number of messages posted by each participant ranged from 1 to 51, with a mean of 9.5 (12.9) messages per participant. The modal number of messages was 1, with 7 out of 23 participants (30.4%) only posting a single message in the forum.

A total of 17 participants (73.9%) were low frequency posters who each posted less than the mean of 9.5 messages per participant, and were collectively responsible for writing 55 out of 221 messages (24.9%). The remaining 6 participants (26.1%) were high frequency posters who each posted more than the mean of 9.5 messages, and wrote 166 out of 221 messages (75.1%).

Due to the large number of messages posted by this relatively small sub-group of participants, the median number of messages may provide a more accurate indication of typical group activity. The median number of messages per participant was 4.

5.3.2.3 Threads per participant

The number of threads created by each participant ranged from 0 to 4, with a mean of 0.7 (1.1) threads per participant. The modal number of threads was 0, with 13 out of 23 participants (56.5%) not creating any new threads of their own. These participants only contributed to discussions that had previously been initiated by other members, by responding to existing postings within the forum. 11 out of 19 threads (57.9%) were created by the 6 high frequency posters who also wrote the majority of forum messages. This indicates that this small group were core members of central importance to the forum, as they were responsible for the majority of threads and postings. The median number of threads created by each participant was 0.

5.3.2.4 Replies received

The number of replies per thread ranged from 0 to 32, with a mean of 7.5 (10.4) replies per thread. The modal number of replies was 1, with 5 out of 17 threads (29.4%) only receiving one reply. Only 3 out of 17 threads (17.6%) did not receive any replies. When a new thread was created, the duration of time before receiving the first reply ranged from 2.2 hours to 11.8 days with a mean of 2.5 (3.3) days.

In longer threads where discussions continued over a period of weeks or months, messages were not evenly distributed over time and were instead posted in bursts. Typically several messages would be written within a relatively short period of time, followed by a pause of inactivity lasting for days or weeks, and then another burst of messages would be written. This pattern was repeated with further pauses and bursts of messages until the discussion was concluded and the thread came to an end.

5.3.2.5 Time of day

The time of day when participants posted messages were distributed fairly evenly, with 116 messages (52.5%) posted during the daytime (7:00am to 5:59pm), 57 messages (25.8%) in the evening (6:00pm to 10:59pm) and 48 messages (21.7%) at night (11:00pm to 6:59am). The time of day when participants created new threads also showed a similar pattern, with 10 threads (52.6%) created in the daytime, 5 threads (26.3%) in the evening, and 4 threads (21.1%) at night.

5.3.3 Introductory messages

Nearly all participants (n=21, 91.3%) used their first forum message to introduce themselves to the community and tell their personal disease story. These messages were all posted in the '*Welcome*' board with the exception of three individuals who posted their first message in the '*Your thoughts and experiences*' board. The remaining two participants did not introduce themselves. One of these used her first message to ask for

advice about disability benefits, and the other was campaigning to increase public awareness of CRPS. Introductory messages were focussed around six themes: Personal details; precipitating event; symptoms; treatment; living with CRPS, and reasons for joining the forum. All quoted extracts are presented verbatim with the original grammar, spelling and language used by participants, so that their voices can be heard in their own words.

5.3.3.1 Theme 1: Personal details

Most participants (n=17, 73.9%) provided some personal and demographic information about themselves, disclosing such information as their name, age, geographical location, occupation, marital status and/or how many children they have. Messages typically started by saying "*Hi*" or "*Hello*" followed by a brief introduction, similar to what might happen at the start of a face-to-face interaction, as demonstrated in the following quotes:

> "*Hi I'm [name], I'm [age] years old married with [number of] kids.*" (Welcome board, thread 1, message 16).

> "*Hi all! I'm a [age] year old pharmaceutical science student in [city]*" (Welcome board, thread 1, message 32).

5.3.3.2 Theme 2: Precipitating event

Just over half of all participants (n=13, 56.5%) talked about the precipitating event that triggered their CRPS, illustrating the diverse range of incidents that can lead to the onset of this illness. Three participants developed CRPS following surgery, three were in a road traffic accident, three had either a fractured or broken bone, two had either a sporting injury or an impact to the affected limb, one experienced numerous medical complications making it difficult to establish what caused her illness, and one participant spontaneously developed the condition without any initiating event.

Some of these descriptions went into considerable detail about the events leading up to their diagnosis and provided a powerful and vivid account of the difficulties that some individuals experience prior to being diagnosed. In the following quote, Reflex Sympathetic Dystrophy (RSD) is an alternative name for CRPS that is typically used in the USA:

> "*I had a car accident 20 years ago […] I originally hurt my left knee it smashed off the dashboard and I was encased in hip to thigh plaster for 8 weeks […] Over the years I have had 11 operations on the left knee and due to how I walked I ended up with a bad right knee spine and arms and shoulders and ankles from using crutches to cut a very long story short I've ended up with a failed right knee replacement which has left me with a bone infection which the dr said he can't source the bug so when it flares it will more than likely kill me nice eh I need a replacement on my left side and have had numerous surgerys to try to sort things out but 8 years ago they found I have Rsd in both my knees and each operation made my pain much much worse to a point that it isn't really controlled. I had an op on my right shoulder which has left it with Rsd and across my neck and down the other arm is playing up same symptoms as Rsd so they now say its in my neck and arms and shoulders my hands are affected too*" (Welcome board, thread 1, message 12).

Other participants provided much shorter descriptions of how they were diagnosed. These individuals typically gave a very brief description of how they developed CRPS, only providing the minimum level of detail needed to convey their experiences, as this quote shows:

"*I came off a motorbike in [year]. I developed CRPS very quickly afterwards and was diagnosed about 6 or 7 months later.*" (Welcome board, thread 1, message 49).

5.3.3.3 Theme 3: Symptoms

Most participants (n=19, 82.6%) described which part of their body was affected by CRPS and what symptoms they experienced.

Where disease location was mentioned, nine participants had CRPS in their lower limbs, five in their upper limbs, and four in both upper and lower limbs. A total of six participants said that their CRPS had spread, either because the affected body area had gradually expanded or because they had developed CRPS in multiple regions of the body, as this quote demonstrates:

"*The initial site being my right hand/arm […]. This gradually spread to my left side although not quite as bad there. Then after 5yrs I had a fall and after a month in hospital suffered a bad spread to my right leg.*" (Your thoughts and experiences, thread 3, message 1).

Typical symptoms included severe pain, burning sensations, heightened sensitivity and/or disproportionate pain in response to touch, swelling, changes in skin colour or temperature, and motor restrictions. The following quote provides a vivid description of some of these symptoms:

"*I have the CRPS now in both feet and legs, both hands and arms, with the mottling across my back and down my left arm and the bone changes and hand changes, swollen feet and legs, dry sore blurry eyes, and spinal pain, tinnitus, dizzyness, vertigo etc. […] It was in [year] the CRPS symptoms of dystonia,*

memory problems, muscle spasms, oedema night sweats, and blinding head pains began." (Welcome board, thread 1, message 5).

5.3.3.4 Theme 4: Treatment

Just over half of all participants (n=13, 56.5%) talked about their past or current treatment regimes, with most individuals having undergone a range of different treatment options including physiotherapy, drug treatment, spinal cord stimulation and specialist courses.

Physiotherapy: Eight participants had undergone physiotherapy to help them overcome the motor limitations associated with their CRPS. Although this treatment approach did not work for everyone ("*Physio was stopped because there was no improvement*", Welcome board, thread 1, message 28), some individuals found it beneficial to use the affected limb as much as possible ("*I keep as active as I can but as it is now in both legs I do use a wheelchair when I want to be out and about doing things; as otherwise the flare ups and muscle weakness (due to many strains that aren't healing)is too much to deal with*", Welcome board, thread 1, message 32).

Drug treatment: Seven participants described using medications to control their pain levels, with limited results. Two individuals said that they had stopped taking pain medication because it did not work for them ("*I gave up trying the painkillers after them just causing side effects with no positive effects*", Welcome board, thread 1, message 2). Other participants described their current drug regime in various levels of detail, ranging from a brief summary ("*I'm on all the meds, standard, all the pain, standard*", Welcome board, thread 1, message 45) through to longer descriptions of specific medications ("*I now manage with daily paracetamol and diclofenac. Then buprenorphine on top as and when required*", Welcome board, thread 1, message 32).

Spinal cord simulation (SCS): Two participants had used SCS to control their pain levels with mixed results. While SCS worked successfully for one individual ("*I was referred, to [hospital] for a spinal cord stimulator. It was wonderful the day it was fitted it was turned on and my pain level went down to bearable*", Welcome board, thread 1, message 16), the other experienced difficulties using this to control her pain ("*[I] am having real problems with my scs. This is my second scs as I burned out the first in 5 months*", Welcome board, thread 1, message 49). Additionally, a third participant had been offered SCS but declined because she wanted to keep this available as a potential treatment option in case her pain deteriorated in the future ("*My pain doc is in talks about giving me an SCS but I'm resisting because I'm managing and I still want options left for the future in case it gets any worse*", Welcome board, thread 1, message 32).

Specialist courses: Six participants had attended specialist courses for pain management and rehabilitation. Two individuals were currently midway through a pain management course ("*I am currently at [hospital] on a four week pain management programme hoping to gain back some control over my body*", Welcome board, thread 1, message 33), while others indicated that attending these courses had helped them to learn more about controlling their illness and setting realistic goals for themselves ("*I was lucky enough to ger funding to stay at [hospital] as an inpatient for 2 weeks. Omg it was mentally, physically, and sometimes soul destroying. But I learnt so much*", Welcome board, thread 1, message 3).

5.3.3.5 Theme 5: Living with CRPS

Most participants (n=16, 69.6%) talked about their experience of living with CRPS, and the impact it has on their daily lives and activities. There was a particular focus on good and bad days, loss of career, and the financial impact of CRPS.

Good and bad days: Fourteen participants described the challenges of living with CRPS and the importance of finding something that gives their lives a positive meaning. Several individuals mentioned the problems of living with constant pain and knowing that their illness cannot be cured ("*I have learnt to live with my CRPS pretty well although I do have bad days when I get very frustrated and upset*", Welcome board, thread 1, message 37). Some participants gradually lost contact with their family and friends as a result of the illness ("*I did find that CRPS ruined my marriage and friends slowly over the years dropped off as I could go out less and less and couldnt do the things with them that I could before*", Your thoughts and experiences, thread 3, message 1). Another common problem was not being able to do hobbies or other normal activities ("*i can't do my hobbies (cycling, hill walking, camping, crafts, pottery) i struggle with my gardening, i struggle with shopping and repairing my home*", Welcome board, thread 1, message 5).

Despite all these difficulties, participants recognised the importance of staying positive and focussing on the important things in life. For some, this involved concentrating on what they can do ("*[I] have stopped looking at life from the aspect of things I cannot do and now look at what I can do as an achievement*", Your thoughts and experiences, thread 3, message 1), realising how lucky they are ("*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 go to uni and get joe jobs have good partners and have good lives so in some respects think myself lucky*", Welcome board, thread 1, message 12) and being inspired to do things that will help other people ("*I hit rock bottom and considered suicide, but then decided I'd got a fantastic wife, kids and friends and instead I am going to work towards setting up a charity*", Welcome board, thread 1, message 16).

Loss of career: Two participants mentioned the impact of losing their career and no longer being able to work due to their CRPS symptoms. This appeared to have a negative

effect on the self-identity of individuals through the loss of previously-important social roles ("*I spent the first 2yrs in depression and mourning the loss of my career and life as it was*", Your thoughts and experiences, thread 3, message 1). Participants also expressed their frustration at not being able to obtain employment that fits in with the limitations of their illness, as this quote shows:

> "*One of my biggest frustrations is not being able to work - having had to leave my job because I had lost the dexterity to do the work - and not as yet being able to find a job I can sustain.*" (Welcome board, thread 1, message 19).

Financial impact: One participant talked about the financial impact of living with CRPS. The illness meant she had higher living expenses because of needing to buy specialist equipment and also having to pay others to do jobs that she could no longer do for herself, and at the same time her income was reduced because she had to rely on social security benefits as her only household source of income. As a result, she was in debt and faced the possibility of losing her home, as this quote explains:

> "*The entire illness so far as cost me all my savings in paying for diy help, decorating help, garden help. taxi fare, adaptations, heating costs, special footware, special socks, special bras, light weight cotton everything, and now looks like it may also cost me the family home as I can no longer afford the bills to keep warm, and can no longer cope in the house alone. […] The dwp have me living on £97 a fortnight, so I am in constant debt due to my health, and the stress of course compounds the rds/crps.*" (Welcome board, thread 1, message 5).

5.3.3.6 Theme 6: Reason for joining

Some participants (n=7, 30.4%) explicitly talked about their reasons for joining the forum, with two individuals giving more than one reason for joining.

Three participants wanted to contribute to scientific research into CRPS ("*I've joined to contribute to the research*", Welcome board, thread 1, message 41), four participants hoped to meet other individuals with CRPS who live in the same geographical area ("*I live in [town] would be interested in meeting some more people around the area.*", Welcome board, thread 1, message 45), and two participants joined because they were looking for support and advice ("*[I] am now at a bit of a dead end. […] Any advise would be greatful, as I don't know where to go from here*", Welcome board, thread 1, message 28).

Being able to interact with others who can understand and relate to the challenges and difficulties of living with CRPS appeared to be particularly important to members, as one participant explained in the following quote:

> "*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).

5.4 Discussion

This study looked at engagement in the Bath CRPS forum. The aims were to identify the pattern of membership growth that occurs when a new online support community is launched, to investigate patterns of engagement through an analysis of message headers, and to investigate how members introduce themselves to the group, the structure of these introductions, and what information they disclose about themselves.

5.4.1 Membership growth

It was anticipated that membership growth might take the form of linear, exponential or burst growth. There was no evidence of either linear or exponential growth. Instead, the

number of participants grew in '*bursts*' where some months had a large increase in membership while other months had very little increase.

The majority of forum growth took place in two distinct bursts, the first in June and the second in September and October, when there were relatively large increases in membership levels. This coincided with the launch of targeted recruitment campaigns designed to increase awareness of the study and attract new members. During the other months of the study there was a gradual background increase of one or two new members per month.

This growth pattern is consistent with research into how people discover online support communities. According to van Uden-Kraan, Drossaert, Taal, Shaw, et al. (2008), most individuals discover forums in one of three ways: either by chance while searching on the Internet for health-related information; by hearing about them from family members or patient organisations, or through direct marketing carried out by the community. The two major bursts in forum growth occurred in response to marketing campaigns that were launched to recruit new members. In contrast, the much smaller levels of background growth may have been associated with individuals who discovered the forum by chance while using an Internet search engine, or who were told about the forum through word-of-mouth from others who were either existing members or have heard about the study.

Based on these findings, it appears that the success or failure of a new discussion forum may be partly influenced by the promotional strategies used to recruit members during and after launch. Growth is the third of the five key stages in the lifecycle of online communities described by Iriberri and Leroy (2009), and follows on from the group's inception and creation. Publicity campaigns promoting a new forum may generate interest and encourage new members to join by making them aware of the forum, its purpose, target audience, and any organisations it might be affiliated with. If enough members join

then the forum may achieve the required '*critical mass*' of members that are needed for discussions to become self-sustaining (Jones et al., 2004; McCarty, 1992).

5.4.2 Header analysis

This forum had 23 participants who produced a mean of 1.0 message per day and 7.5 replies per thread. In comparison, established online support communities typically have a greater number of members, may produce more messages per day but can receive fewer replies per thread. For example, an eating disorders group with 70 members produced 4.4 messages per day and 6.4 replies per thread (Winzelberg, 1997), and groups for arthritis (16,000 members), attention deficits (18,000 members) and depression (23,000 members) produced an overall mean of 74 messages per day and 3.5 replies per thread (Galegher et al., 1998).

There appears to be a positive relationship between the number of forum members and how many messages are posted per day, where smaller groups may produce fewer messages per day because there are fewer members for individuals to interact with. In contrast, the relationship between membership size and the number of replies received may be more complicated, with smaller forums appearing to receive more replies than larger established groups. There are two possible explanations for this. One possibility is that the number of replies received may be unrelated to membership size but could instead reflect the supportive intentions and behaviours of members, where a more supportive group may produce a greater number of replies. In the studies by Winzelberg (1997) and Galegher et al. (1998), it might simply be a coincidence that the larger groups happened to produce fewer replies. Alternatively, there could be a negative relationship where larger groups produce fewer replies because of diffusion of responsibility.

Diffusion of responsibility (Darley & Latané, 1968) occurs when the presence of a large number of observers leads to a reduced likelihood of someone helping, and has been

found to occur on the Internet. For example, Barron and Yechiam (2002) sent help requests by e-mail to either single or multiple recipients, and found that e-mailing multiple recipients reduces both the number of replies received and the helpfulness of those replies. In a similar study, Yechiam and Barron (2003) e-mailed help requests to either single recipients or an e-mail ListServ that automatically forwards e-mails to all members. They found that individual recipients were nearly three times more likely to help than ListServ members, and ListServs with a larger number of members were less likely to help than those with a smaller number of members.

There are two possible explanations for why this might occur (Yechiam & Barron, 2003). One possibility is that larger groups produce a greater volume of messages with more requests for help. This increases the time commitment needed to read messages and compose replies, and if an individual only has limited time or resources available then they become much less likely to respond to any particular message. Alternatively, knowing that a group has a large number of members who could potentially reply may lead to a widespread perception that replying is less important. In effect, individuals may '*learn*' that they do not need to reply to as many messages. At the present time, little is known about if or how these explanations might be expressed within discussion forums.

The mode and median number of threads created was 0, showing that most participants commented in discussion threads created by other individuals and did not start any new threads of their own. This suggests that providing social support to other individuals and helping them with their difficulties may have been an important part of the forum. Individuals may not have joined the forum with the sole intention of creating new threads to discuss their own problems and instead used it to provide each other with support.

In longer discussion threads, messages were often posted in '*bursts*'. Typically, several messages would be written within a relatively short period of time, followed by days or

weeks without any activity, and then another burst of messages would continue the discussion. It is unclear what caused this pattern or if the same phenomena occurs in other forums.

Just over half of forum messages and threads were created during the daytime, with a high proportion of forum use also taking place during the evening and at night. This is similar to the usage patterns that have been found in established online support communities. Boberg et al. (1995) reported that individuals with cancer used the CHESS system at all hours of the day and night, with particularly heavy use in the evenings. Similarly, Winzelberg (1997) found that 37% of messages in an eating disorder community were posted in the daytime, 32% in the evening, and 31% at night. These findings suggest that forums and other types of online support community allow individuals to access support at any time of the day or night (Malik & Coulson, 2008a), therefore making it possible to fit their support needs around other obligations like family, work or study commitments (Coulson, 2013; Coulson & Knibb, 2007).

5.4.3 Introductory messages

Nearly all participants introduced themselves to the forum by using their first posting to tell their disease story. These richly detailed descriptions of their CRPS-related experiences had six key features: personal details; precipitating event; symptoms; treatment; living with CRPS, and reasons for joining the forum.

5.4.3.1 Personal details

73.9% of participants provided some personal information about themselves such as their name, age, geographical location and/or marital status. This may have helped to overcome one of the limitations of taking part in forums. Non-verbal social cues like physical appearance, facial expressions and tone of voice are hidden when using discussion forums and other text-based methods of electronic communication (Coulson &

Knibb, 2007; Finfgeld, 2000; White & Dorman, 2001). Explicitly describing personal characteristics like an individual's name or age may be a substitute for not being able to observe these details visually. Previous research indicates that the members of online support communities sometimes find it difficult talking to strangers about their illness (Coulson, 2013), so providing personal details may reduce anonymity and hence make it easier for participants to interact with one another and share information about their experiences.

5.4.3.2 Precipitating event

56.5% of participants said what triggered their CRPS, revealing a diverse range of causes such as surgery, road traffic accidents, fractured or broken bones, sporting injuries or an impact to the affected limb, and spontaneously developing the condition. This reflects the findings of epidemiological studies into CRPS, which have identified fractures (49% of individuals), soft tissue injuries such as sprains (20%), surgery (11%), tendon injuries (6%) and other types of injury (6%) as precipitating events, with 8% of cases occurring spontaneously (de Mos et al., 2008).

5.4.3.3 Symptoms

82.6% of participants described their affected body area and what symptoms they experience. Nine participants had CRPS in their lower limbs, five in their upper limbs, and four in both upper & lower limbs. This differs slightly from the normal pattern, with epidemiological studies indicating that CRPS occurs most commonly in the upper limbs (de Mos et al., 2007; Sandroni et al., 2003). However, in the present study, CRPS occurred more commonly in the lower limbs, although the reasons for this are unclear. Nevertheless, the symptoms described by participants in this study are typical of those normally associated with this illness (Harden et al., 2007; McCabe & Blake, 2008; Turner-Stokes & Goebel, 2011).

5.4.3.4 Treatment

56.5% of participants provided information about their past or current treatment regime. Four approaches to treatment were mentioned: physiotherapy, drug treatment, spinal cord stimulation, and specialist courses. This closely reflects the literature on CRPS treatment, with reviews of potential treatment strategies indicating that paramedical interventions like physiotherapy can be effective, drug treatment is often used to control pain but there is mixed evidence of its effectiveness, and invasive treatments like spinal cord stimulation can reduce pain but do not improve functioning (Cossins et al., 2013; Hord & Oaklander, 2003; Perez et al., 2010), while specialist courses and rehabilitation programmes may be particularly beneficial to help individuals learn how to control their CRPS (Rodham et al., 2012).

5.4.3.5 Living with CRPS

69.6% of participants talked about their experience of living with CRPS and the impact it has on their daily lives. These descriptions focussed on good and bad days, loss of career, and financial impact. Participants talked about the problems of living with constant pain and losing contact with family and friends, which reflects previous research indicating that CRPS can have a severe impact on quality of life (Galer et al., 2000) and can lead to social isolation (Rodham et al., 2009). Additionally, they talked about the importance of being positive and focussing on what they can do, supporting one of the themes '*focussing on the positive*' that arose in a previous study of online social support for CRPS (Rodham et al., 2009). Some participants mourned the loss of their career and said that they still wanted to work despite the limitations of their illness. Participants also experienced higher living expenses together with a loss of income. This supports the findings of a study conducted in the Netherlands that examined the impact of CRPS on employment and household incomes (Kemler & Furnée, 2002), which showed that few

individuals with CRPS were able to continue working and the illness put a considerable strain on household finances.

5.4.3.6 Reason for joining

30.4% of participants explicitly mentioned their reason for joining the forum. Participants wanted to contribute to scientific research, meet others, and seek support and advice. CRPS is an unpleasant and debilitating illness, and it appears that some individuals may have a desire to contribute to research studies investigating this condition to lead to an improved understanding of the physiological mechanisms underlying the illness, and how it can be managed and treated. Wanting to meet others or seek support and advice are acknowledged in the literature as common reasons for joining online communities (Coulson, 2013; Ridings & Gefen, 2004).

In her theory of online support, LaCoursiere (2001) introduced the concept of initiating events by saying that a change in the individual's health status or perceived health triggers them to seek online social support (see Section 2.4.2). These results expand her findings by suggesting that a change in health status is not the only reason why individuals are prompted to join an online support community. Instead, there can be a diverse range of reasons for joining and some individuals may have more than one reason.

5.4.3.7 Summary of introductory messages

Overall, telling their disease story may have served the wider purpose of creating legitimacy and establishing authority within the forum (Armstrong et al., 2012; Galegher et al., 1998). According to Galegher et al. (1998), anybody can join an online community but nobody has a duty to acknowledge or help newly joined members. This means new members may need to demonstrate their legitimacy and show why they should be accepted by expressing real and genuine concerns. Telling their disease stories may have

allowed participants to provide personal details about themselves to show they are real people, and also claim membership through behavioural statements about how they were diagnosed, what symptoms they experience, their treatment regime, the impact it has on their lives, and their reasons for joining the forum. Establishing their credentials in this way may have helped them to demonstrate authority, showing why others should read their messages, listen to their advice and take their comments seriously.

These results extend the findings of Rodham, Gavin, Coulson, et al. (2013), who used the Bath CRPS forum to look at introductory messages in the context of identity formation. Their study identified five themes: journey to diagnosis, treatment, contact with health care professionals, looking for the positive, and hobbies. Most of the themes from Rodham, Gavin, et al. are reflected in the current findings. Their '*journey to diagnosis*' theme is conceptually very similar to the '*precipitating event*' theme in the present study. Both themes describe the events leading up to the individual being diagnosed, with the '*precipitating event*' theme building upon this by also looking at the precipitating event that triggered the illness. Their '*treatment*' and '*contact with health care professionals*' themes examined participants' experiences of various treatment methods and their encounters with healthcare professionals, while the present study focusses in greater depth on the different treatment options undertaken by participants. Their '*looking for the positive*' theme was expanded to form part of the wider theme '*living with CRPS*' in the present study. However, their final theme '*hobbies*' is not reflected in the present findings because, although this was an important component of building a shared identity, it did not form an integral part of participants' disease stories.

5.4.4 Limitations and future research

5.4.4.1 Membership growth

Membership growth was examined by looking at the date when each participant posted their first message, which was used to work out how many new members joined the forum each month. Unfortunately we did not have access to the exact date when each participant registered with the forum, so there is a possibility that some individuals did not post their first message during the same month that they joined. For example, some individuals may join a forum and then spend time '*lurking*' before posting messages of their own, to give themselves time to feel comfortable and get used to the group (Colvin et al., 2004; Winzelberg, 1997). Consequently, these findings should be considered tentative. Future research is needed to examine membership growth using an online community where the registration date is available for all participants, to develop a more accurate picture of how forum membership grows and develops after a new community has been launched.

5.4.4.2 Header analysis

Header analysis revealed that most group activity was produced by a core group of 6 high frequency posters. This meant that a relatively small sub-group of participants produced a large proportion of the dataset. It is unclear how well the data from these participants reflects the online activities of all participants who took part in the study, or how closely the results can be generalised to other online communities.

One possible explanation for the observed negative relationship between membership size and the number of replies received is diffusion of responsibility. At the moment this is just one possible explanation for what was observed, and there is no evidence to support it. Future research could look for evidence of diffusion of responsibility in forums, and there are two potential ways of doing this. First, a study could collect data on the number

of members and mean number of replies per thread across a wide range of online support communities, to see if a negative relationship between membership size and number of replies can be confirmed. If a negative relationship does not exist then this would reject diffusion of responsibility as a possible explanation. Second, a questionnaire survey could be used to investigate attitudes towards replying and actual posting behaviour in communities with small and large membership bodies, to see if any differences emerge that might provide evidence of diffusion of responsibility.

Most participants posted messages in existing threads and did not start any new threads of their own. Moreover, the number of replies per thread was higher than what has been observed in other studies. This indicates that individuals may have wanted to provide each other with a high level of support by commenting on other people's problems rather than starting new threads to discuss their own difficulties. To date, no studies have examined the social support content of messages in CRPS forums, so little is known about what kind of social support members exchange within these groups. There is an urgent need for a content analysis of forum postings to investigate what percentage of messages contain some form of social support, what types of support are present, and how this support is expressed. It is anticipated that the low number of threads created per participant together with the high number of replies per thread may be associated with high levels of social support within postings. Consequently, these social support issues will be examined in Chapter 6.

5.4.4.3 Introductory messages

Introductory messages took the form of disease stories, with participants talking about their personal details, precipitating event, symptoms, treatment regime, their experience of living with CRPS, and their reasons for joining the forum. This data was taken from a closed forum which had high levels of privacy with no public access, and it is unclear

whether introductory messages would contain the same level of disclosure in open forums where messages can be publically viewed by anybody who chooses to read them. Further research will be needed to investigate whether these findings can be generalised to other online support communities, such as open discussion forums for CRPS and other health conditions.

5.4.4.4 Sociability issues

Only a relatively small number of participants joined the forum, which can be partly explained in terms of sociability. The sociability of online communities depends on three factors: purpose, people and policies (Preece, 2001). The purpose of the forum was a research project, and while some participants cited this as a reason for joining, others may have been reluctant to join because they were not comfortable with being '*studied*' (Eysenbach & Till, 2001).

The policy of using a closed forum meant individuals had to register before they could view messages and assess whether the forum was suitable for their needs, which may also have discouraged some individuals from joining. In relation to people, activity levels were lower than what has been observed in other groups (Galegher et al., 1998; Winzelberg, 1997), indicating that the forum failed to develop into a true community. This failure may have been partly due to low uptake, with the forum failing to achieve the '*critical mass*' of members needed for discussions to become self-sustaining (Jones et al., 2004; McCarty, 1992), and partly because of the hacking incident that occurred midway through the study. The hacking incident severely disrupted communication within the forum, illustrating how incidents of this type may have an impact on members. Participants may have subsequently felt that the forum was no longer a '*safe*' place for them to use, and the forum did not recover.

5.4.4.5 Use of other online social media

Participants used other social media outlets like Facebook groups alongside the forum. After the study ended they were offered the opportunity to continue running the forum but chose not to do this. This is partly because the forum did not recover from the hacking incident, but there might also be another explanation: individuals may have preferred the convenience of using Facebook on their mobile phone or tablet computer, rather than logging onto a PC to use the forum. Future research should investigate what social media platforms people prefer, and how this influences engagement with those platforms and what kind of online support they receive.

5.5 Conclusions

Membership growth plays an important role in the success or failure of newly launched online support communities, with forums needing to achieve a '*critical mass*' of members for discussions to become self-sustaining. Growth occurred in '*bursts*' that were closely linked to the promotional strategies used to increase awareness of the forum and recruit new members, indicating that the development and implementation of a successful marketing strategy may form a crucial part of successfully launching a new forum.

Header analysis demonstrated how individuals with CRPS use forums. Messages were posted during the daytime, evening and at night, showing that forums can be used to access support at times when other sources of support might not be available. Participants provided support to other individuals, in addition to receiving support for their own difficulties. One possible explanation for the pattern of replies is that diffusion of responsibility may occur in discussion forums, with larger forums appearing to receive fewer replies than smaller forums.

Introductory messages can be crucial for whether newly joined individuals continue to engage with the forum. Individuals used their first forum message to tell their '*disease*

story', focussing on six themes: personal details, precipitating event, symptoms, treatment, living with CRPS, and reasons for joining. This served the dual purpose of establishing their legitimacy as members, and asserting their authority by showing why others should read their postings and take their views seriously.

Chapter 6: Study 2 – An examination of social support processes within a newly-created CRPS online forum

Abstract

This study examines the support content of messages and how support processes become established in a newly launched CRPS online forum. Content analysis was used to code messages using the Social Support Behavior Code (Cutrona & Suhr, 1992, 1994). Emotional support was the most common (present in 73.8% of messages), followed by informational (34.8%), esteem (31.2%) and network support (7.2%), with tangible aid occurring only rarely (2.3%). 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*'.

6.1 Introduction and research aims

As discussed in Chapter 1 (Section 1.2.5.4), some individuals with CRPS experience difficulties taking part in social and recreational activities (Galer et al., 2000), which can leave them with a greatly reduced social network and limited opportunities for obtaining social support (Rodham et al., 2009). Online support communities, which were discussed in Chapter 2, may provide individuals living with CRPS with an alternative way of obtaining social support.

This study investigates social support processes in the Bath CRPS forum by looking at how support processes become established when a new forum is launched, and how online support can contribute to illness management through the CRPS '*four pillars of intervention*' (Section 1.2.4.5).

6.1.1 How support processes become established

Section 5.1.2 outlines Iriberri and Leroy (2009)'s five stages in the lifecycle of online communities. Their third stage, growth, is critically important for how support processes become established after a new online support community is launched, because this is when members begin to interact with one another and exchange their first supportive messages. 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. Consequently, the first research aim for this study is to investigate how support processes become established when a new online support community is launched.

6.1.2 Optimal matching theory

As discussed in Chapter 2, online support communities let members communicate by using the Internet to exchange 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.

Optimal matching theory (Section 2.4.3) is an important theory for understanding how individuals benefit from social support received over the Internet. In particular, it distinguishes between action-facilitating support and nurturant support, with several studies of online support communities indicating that action-facilitating support helps

people with the controllable aspects of a health condition while nurturant support helps with the uncontrollable aspects (Braithwaite et al., 1999; Coulson, 2005; Coulson et al., 2007; Coulson & Greenwood, 2012; Eichhorn, 2008; Malik & Coulson, 2008a). To date, no studies have been conducted that use optimal matching theory to examine the support content of messages in CRPS forums. Consequently, the second research aim for this study is to examine the support content of messages in the context of optimal matching theory.

6.1.3 CRPS Four pillars of intervention

There are several advantages to receiving social support over the Internet (Section 2.3.3), 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, 2010b).

If individuals with CRPS benefit from engaging with online support communities, then the CRPS '*four pillars of intervention*' might provide a framework for understanding what benefits they receive and how this contributes to illness management. As explained in Section 1.2.4.5, the '*four pillars*' of education, pain relief, rehabilitation and psychological interventions represent the '*gold standard*' for managing and treating CRPS. To date, no studies have examined how online support communities might contribute to the '*four pillars of intervention*'. Consequently, the

third research aim for this study is to investigate how social support received over the Internet contributes to the CRPS '*four pillars of intervention*'.

6.2 Methods

6.2.1 Data collection

The data for this study was collected as part of the Bath CRPS forum described in Chapter 4. This study used all 221 messages that were posted in the '*Welcome*' and '*Your thoughts and experiences*' boards, as outlined in Section 4.2.3.

6.2.2 Participants

The participants were all 23 active participants from the Bath CRPS forum, as described in Section 4.2.4.

6.2.3 Analysis

The initial data preparation was carried out as described in Section 4.2.3.

Content analysis (Elo & Kyngäs, 2008; Pfeil & Zaphiris, 2010) was used to examine the social support content of messages. This can be done using either an inductive (bottom up) or deductive (top down) approach, as discussed in Section 3.1.8.3. Inductive coding involves deriving the social support categories from the dataset, which ensures that the analysis will encompass all the different types of support that are present in those messages but the results will lack standardisation. Deductive coding involves coding the messages into an existing social support framework, which makes it easier to compare the results across studies but with a possibility that some types of support could be overlooked if they are present in the messages but not in the coding framework.

A deductive (top down) approach was used to code the data into existing social support categories derived from the Social Support Behavior Code (SSBC) (Cutrona

& Suhr, 1992, 1994). 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 sub-categories 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 was originally developed to assess the frequency of face-to-face supportive behaviours between spousal couples, and consists of five main categories of social support that are further divided into twenty-three sub-categories of support-intended communication behaviour. Table 3 shows the full list of categories and their original definitions. There are slight differences in sub-categories between the 1992 and 1994 versions of the SSBC. The 1992 version lists '*referral*' as a type of informational support, and '*listening*' and '*encouragement*' as types of emotional support. These are not present in the 1994 version, which instead adds '*express concern*' and '*reassurance*' as types of emotional support, and '*comply with request*' as a type of tangible aid.

Table 3: Original categories and definitions of the Social Support Behavior Code.

Support type	*Cutrona & Suhr (1992), p. 161.*	*Cutrona & Suhr (1994), p. 122.*
Informational support		
Suggestion/advice	Offers ideas and suggests actions	Offer ideas, suggesting actions
Referral	Refers the recipient to some other source of help	n/a
Situation appraisal	Reassesses or redefines the situation	Reassess the situation
Teaching	Provides detailed information, facts, or news about the situation or about skills needed to deal with the situation	Teach how to do something or teach facts
Emotional support		
Relationship	Stresses the importance of closeness and love in relationship with the recipient	Express closeness or togetherness
Physical affection	Offers physical contact, including hugs, kisses, hand-holding, shoulder patting	Hug, kiss, hand hold, touch
Confidentiality	Promises to keep the recipient's problem in confidence	Promise not to tell others
Sympathy	Expresses sorrow or regret for the recipient's situation or distress	Express sorrow and regret for situation
Listening	Attentive comments as the recipient speaks	n/a
Understanding/empathy	Expresses understanding of the situation or discloses a personal situation that communicates understanding	"I understand", self-disclose
Encouragement	Provides the recipient with hope and confidence	n/a
Prayer	Prays with the recipient	Pray with person
Reassurance	n/a	Nonspecific comfort
Esteem support		
Compliment	Says positive things about the recipient or emphasizes the recipient's abilities	Emphasize abilities, say positive things
Validation	Express agreement with the recipient's perspective on the situation	Agree with and take other's side
Relief of blame	Tries to alleviate the recipient's feelings of guilt about the situation	Say it's not other's fault
Network support		
Access	Offers to provide the recipient with access to new companions	Offer to spend time with person, be there
Presence	Offers to spend time with person, to be there	Offer to provide access to new companions
Companions	Reminds the person of availability of companions, of others who are similar in interests or experience	Others who have been through same
Tangible aid		
Loan	Offers to lend the recipient something (including money)	Offer money or material object
Direct task	Offers to perform a task directly related to the stress	Offer to do something related to problem
Indirect task	Offers to take over one or more of the recipient's other responsibilities while the recipient is under stress	Offer to do something not related
Active participation	Offers to join the recipient in action that reduces the stress	Offer to join in reducing stress
Willingness	Expresses willingness to help	Express willingness to help anytime
Comply with request	n/a	Agree to do something after stressed person requests it

The SSBC 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 sub-categories 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).

Researchers typically use a modified version of the SSBC coding framework that has been adapted for online use. Earlier studies made several changes to the SSBC sub-categories. For example, Coulson et al. (2007) made six changes to the coding framework: For emotional support, the '*listening*' sub-category was removed and '*physical affection*' was changed to '*virtual affection*'. For esteem support, '*anchorage*' was created as a new sub-category. For network support, '*validation*' was removed and recoded as a combined '*validation/empathy*' sub-category of emotional support, and '*relief of blame*' was moved from esteem to emotional support. For tangible aid, '*express willingness*' was moved from tangible aid to network support. Similarly, Mo and Coulson (2008) made four changes: For informational support, '*sharing own experience*' was created as a new sub-category. For emotional support, the '*listening*' sub-category was removed, and '*expression of care*' was created as a new sub-category. For network support, '*presence*' and '*companionship*' were merged into a single sub-category.

More recently, studies of online social support have returned to the original SSBC categories with only minimal changes for online use. For example, Coulson and Greenwood (2012) and Coursaris and Liu (2009) both made only one change to the

coding framework, to remove the '*listening*' sub-category of emotional support. This broadly reflects the changes between the 1992 and 1994 versions of the SSBC, where the '*listening*' sub-category was also removed (Cutrona & Suhr, 1994).

Table 4: Social Support Behavior Code, from Coulson & 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

For this study, the SSBC categories were operationalized using the same definitions as Coulson and Greenwood (2012), as shown in Table 4. 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.

6.2.4 Ethical considerations

The ethical issues for this study are identical to those described in Section 5.2.4.

6.3 Results

6.3.1 How support processes become established

Table 5 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 results show that 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 5: 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 in March 2012 were posted by administrators before the forum was launched.

6.3.2 Social support

Table 6 shows the number of forum postings in each category of social support.

Table 6: Social support content of postings.

	Welcome board		*Your thoughts and experiences board*		*Overall*	
Support type	*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

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. In the following analysis, all illustrative quotes are presented verbatim using the language, spelling and grammar employed by forum members.

6.3.2.1 Emotional support

Emotional support was present in 73.8% of postings. Five of the seven sub-categories 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, how they came to be diagnosed with CRPS, and discuss the difficult and complex issues involved in living with this debilitating illness. Others showed their understanding by disclosing similar information about themselves, after which the member who wrote the initial message would often post subsequent replies giving further information. This led to a shared understanding that was expressed through a high level of empathy. In an exchange that was typical of this process, a new member introduced herself by posting the following message:

> "*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).

She quickly received a reply from another member who expressed her understanding by comparing the original poster's experiences with her own, saying:

> "*Im your other half lol!! Mine is in my right hand up to my shoulder and yep Im right handed too. Wow how lucky were you to be diagnosed that quick. Im not a piano player, but many many years ago I could play the bagpipes, and thats something, as Ive no ties to Scotland, and Im a born and bred [name of town]*" (Welcome board, thread 1, message 20).

This led the first poster to disclose additional details about her experiences, as illustrated in this reply:

> "*Perhaps we could do a weird duet with our musical skills haha!!I've never tried bagpipes - my only link with Scotland is that I enjoy porrige for breakfast! - though I've had a go on quite a few different instruments...I'm a bit frustrated now because I keep trying to play my flute - couldn't play properly before, but having great difficulties now - and can't put my fingers on guitar frets any more..perhaps we should start a band and team up with people with spare hands lol !*" (Welcome board, thread 1, message 21).

Members appeared to derive great meaning from these exchanges, as this quote illustrates: "*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 messages like "*Gentle hugs.xx*" (Welcome board, thread 1, message 13) and "*Warm hugs to you all*"

(Welcome board, thread 2, message 1). The most frequent 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. 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). Similarly, a member spoke of her determination to walk without the aid of sticks or crutches, and received a reply that said, "*I fully believe that you will acheive your goal*" (Welcome board, thread 1, message 8).

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. One reply said, "*Stick to the hydrotherapy it is good for us I guess*" (Your thoughts and experiences board, thread 8, message 4), while another member added, "*I find hydrotherapy really helps and so much easier to do exercises in the water than on land*" (Your thoughts and experiences board, thread 8, message 6).

Sporting activities also received a lot of encouragement. A member described how she refused to give up horse riding and so learned how to ride side saddle, leading to the reply, "*Am really pleased to hear that you have found an alternative way to ride your horse & keep enjoying it*" (Welcome board, thread 1, message 38). Members also offered encouragement through messages such as "*I hope things are going well for*

you at the moment" (Your thoughts and experiences board, thread 18, message 25) and "*Wishing us all a good day*" (Welcome board, thread 1, message 31).

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). Other members also made similar comments, for example: "*I'm really pleased to see this forum, it helps to know there are lots of people in similar circumstances - not that I'd wish this on anyone, but I'm sure everyone knows what I mean*" (Welcome board, thread 1, message 49). Another summed it up 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 receiving a CRPS diagnosis, 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).

Sympathy was sometimes expressed when members described the severity of their symptoms or said that they had problems coping with the illness. For example, when a new member introduced himself and stated that he was finding it very difficult to cope

with CRPS, a respondent replied, "*Sorry to hear you are having such a tough time at the moment*" (Welcome board, thread 1, message 68).

Other messages often related to reduced opportunities for individuals with CRPS, and not being able to take part in some activities. A member who had to give up a much-loved sport because of her CRPS symptoms received a reply that said, "*So sorry you have had to give up wheelchair basketball, I hope you find another sport*" (Welcome board, thread 1, message 55). Similarly, when a member revealed that she was a university student, she received the reply, "*I am sorry you are having to deal with pain instead of hangovers and fun*" (Your thoughts and experiences board, thread 14, message 13).

6.3.2.2 Informational support

Informational support was present in 34.8% of postings. All four sub-categories 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 limbs, joints and other bodily areas that have been affected by CRPS, rather than avoiding using them because of the pain. This is illustrated in the following quote, which was written in reply to a female with CRPS in her lower leg and foot: "*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).

Members sometimes suggested using strategies like knitting to keep CRPS-affected hands active, for example, "*An OT at [hospital] gave me knitting needles as a therapy,*

my left hand has to work first to get my right hand working, and would you believe it, it works" (Welcome board, thread 1, message 3). Another suggestion was to get involved with sporting activities for disabled people, as demonstrated in this quote: "*I have just joined [name of organisation] and they have been fantastic I push through the pain down my left leg but it's worth it, feels like I can move freely again!*" (Welcome board, thread 1, message 46).

Members frequently provided advice about the importance of pacing. The word '*twinkle*' was adopted as a euphemism for pacing within the group. This led members to urge one another to twinkle and avoid overdoing things, as this message shows: "*Remember to pace "Twinkle" especially at the moment because stress causes pain. You must be kind to yourself*" (Your thoughts and experiences board, thread 1, message 12). 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).

Medication was often discussed on the forum, with members sharing information about their drug regimes. For example, while discussing the advantages and disadvantages of taking medications, one member said, "*If taking pills helps with mobility then I personally would keep taking them*" (Your thoughts and experiences board, thread 1, message 6).

Another important area of advice concerned disability aids, with members exchanging thoughts, ideas and suggestions for things that made their lives easier. One member described the benefits of using an electric wheelchair, saying, "*I have bought an electic wheelchair as I have crps in both legs and my left shoulder/arm. The sense of*

freedom is amazing" (Your thoughts and experiences board, thread 18, message 9). Others recommended using special cutlery like a spork, as this quote shows: "*I need a stainless steel 'Spork' so as I dont need my hubbie cut my dinner up whilst in a restaurant. At home I use a plastic one*" (Your thoughts and experiences board, thread 18, message 1). Another common suggestion was to use an e-book reader to avoid the discomfort of holding a book in the hands: "*I have a Kindle, (I cant hold books)*" (Your thoughts and experiences board, thread 13, message 2).

Situation appraisal messages helped members to reassess their situation, putting things into a more positive perspective. Despite the debilitating problems experienced by individuals with CRPS, members often urged one another to focus on the important things in life like family and loved ones. As this member explained:

> "*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 go to uni and get joe jobs have good partners and have good lives so in some respects think myself lucky*" (Welcome board, thread 1, message 12).

Another member expressed similar sentiments about her new pet, saying:

> "*holding my very soon to be 7 week old puppy, (amazing! fitted in my hand and after a moments shyness soon began affectionately licking my chin and snuggling up Very lucky indeed! When your looking to give up the most amazing thing happens.... someone or something loves you despite all and I guess thats what we all need... To that effect I am lucky*" (Welcome board, thread 1, message 25).

After reassessing his situation, one member was inspired a member to look into the possibility of setting up his own charity. As he explained:

> "*I hit rock bottom and considered suicide, but then decided I'd got a fantastic wife, kids and friends and instead I am going to work towards setting up a charity with the aim of educating medical professionals about CRPS and how the sufferers should be treated and raise funds for research in the hope that a cure can be found*" (Your thoughts and experiences board, thread 1, message 14).

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).

Another member also talked about the sense of relief that came with being diagnosed, and also the problems associated with having an illness that is not well understood:

> "*Finding out what it finally was was a relief in so far as it finally had a name and wasn't all in my mind (left my former GP over this). However, diagnosis with a little understood and little supported illness now means I have to keep explaining myself to people and have upward fights with the dwp etc*" (Welcome board, thread 1, message 5).

Other messages helped members to understand their situation by stressing the importance of setting achievable goals and not letting the illness take control of their

lives. "*im not going to allow THIS to take away any more of my life. I now have goals, sensible goals*" (Welcome board, thread 1, message 3). Pacing again formed an important part of this process, with one member saying, "*I have a real tendency to boom and bust and will need to get to grips with that wonderful word "pacing"*" (Welcome board, thread 1, message 33).

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 and statistics for how many people have this illness, as shown in this message:

> "*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. Longstanding CRPS affects about 1 in 5,000 people in the UK*" (Your thoughts and experiences board, thread 1, message 21).

One member emphasised the importance of being sceptical about horror stories and other unverified sources of information that can be found 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 ect...) then there is a potential for the info to be unresearched or not evidenced based*" (Your thoughts and experiences board, thread 13, message 12).

A smaller number of teaching messages were concerned with various aspects of using the forum, to help members get the most out of the online community. For example, a message explained how to use the personal messaging facility of the forum: "*Go to the top of page and click on "mem cp" scroll down and "pm" is listed...not sure how well it works, we had trouble with txt ect, went for old fashioned e-mail in the end*" (Welcome board, thread 1, message 64).

Referral messages directed members to other sources of information. Most referrals were to websites and organisations provide additional knowledge and information. For example, a member looking for a leaflet about CRPS to store on his medic alert flash drive was directed a charity website: "*If you don't already have leaflets, the Arthritis Research site has the info from their's online I think, it's a pretty good one and is the one my rheumatology department have on the condition*" (Your thoughts and experiences board, thread 6, message 3).

Some referrals helped members to save money when buying pet supplies or other items. During a discussion about pets and the important role they can play in member's lives, a respondent posted a link to a website that provides cheaper pet supplies: "*A good website for everything from beds to toys to food is zooplus.com. I use it all the time as you can make some big savings and much cheaper than pets at home*" (Welcome board, thread 1, message 47).

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).

6.3.2.3 Esteem support

Esteem support was present in 31.2% of postings. Two of the three sub-categories 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 had seen people in more pain and dismissively advised him 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 be able 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). Members also supported and defended each other in a light-hearted way about shopping decisions. During a discussion about the benefits of comfortable footwear, one member commented that it was an excuse for buying lots of shoes, and she immediately received a reply saying, "*any excuse for shoes, I sooooooooo with you on that one*" (Your thoughts and experiences board, thread 18, message 5).

Compliment messages expressed positive things about the recipient and what they have achieved despite living with CRPS. When a member mentioned that she was preparing for possible inclusion in the Paralympics, others were quick to applaud her with one reply saying, "*Good luck with the Paracycling assessment, what your doing is fantastic*" (Welcome board, thread 1, message 62). Similarly, when a member bought an electric wheelchair and was able to follow a cliff path to the beach for the first time in years, a member replied, "*congrats on your freedom, it makes each day an easier day lol*" (Your thoughts and experiences board, thread 18, message 10). Other

messages followed similar themes, like complimenting a member for successfully managing her CRPS without needing to take any medication by saying, "*would like to say how lucky are you*" (Your thoughts and experiences board, thread 1, message 4). A member who was able to continue working in a secondary school despite living with CRPS was told, "*Wow you're brave, I could never work in a secondary school!*" (Your thoughts and experiences board, thread 14, message 14).

6.3.2.4 Network support

Network support was present in 7.2% of postings. All three sub-categories 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 as demonstrated in this quote, "*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 by saying, "*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, one new member explained that she joined to contribute to research and received the reply, "*I look forward to chatting and getting to know you*" (Welcome board, thread 1, message 43). When another 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 in the data. During a discussion about accessibility problems and outdoor activities, two members realised they lived close to each other and replied saying, "*[It] would be great to bump into one another*" (Your thoughts and experiences board, thread 18, message 17).

6.3.2.5 Tangible aid

Tangible aid was present in 2.3% of postings. Three of the five sub-categories 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 to 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). Another form of direct assistance occurred when a member offered to create a new thread to discuss gadgets and other disability aids that member's found useful, saying, "*Will start a new list where we can all bed just the adaption and what use*" (Your thoughts and experiences board, thread 18, message 23).

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 have got 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).

6.4 Discussion

This study investigated online social support in a newly launched CRPS discussion forum. The aims were to investigate how support processes become established, examine the support content of messages in the context of optimal matching theory, and investigate how social support received over the Internet contributes to the CRPS '*four pillars of intervention*'.

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, 2015b) and middle-aged people are more likely to use the Internet for health-related purposes (Andreassen et al., 2007; Baker et al., 2003; Ybarra & Suman, 2006), so one might expect forum members to be slightly younger than what is normally found in the CRPS population.

6.4.1 How support processes become established

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 (Section 6.1.1). 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 (Algazi, 2000; Dickerson, Posluszny, & Kennedy, 2000; Shatan, 1973).

6.4.2 Social support

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%).

6.4.2.1 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 sub-category 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.

6.4.2.2 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 websites 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. Those with uncontrollable problems should benefit more from emotional support because this will

help them to cope with the 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; Rodham, McCabe, et al., 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.

This is also consistent with the uses and gratifications model, discussed in Section 2.4.4. Participants had informational and emotional support needs that were not being met by their existing resources, and they used the Bath CRPS forum to fulfil those needs (Lee & Hawkins, 2010).

6.4.2.3 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).

6.4.2.4 Network support

Network support was present in 7.2% of messages. These messages reminded members that they are not alone in their experiences, and emphasised 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.

6.4.2.5 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.

6.4.3 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*' (Goebel et al., 2012; 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 well-being of members.

6.4.4 Limitations and future research

There were several limitations in this study, which lead to a number of suggestions for future research.

6.4.4.1 Participant characteristics

Just over half of registered forum 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 et al., 2011).

A possible explanation for the importance of core members relates to the distinction between explicit and implicit norms in virtual communities (Burnett & Bonnici, 2003). Social norms define the attitudes and behaviours that are considered to be acceptable for members of an online community, and can vary from one community to another. Explicit norms refer to rules that are outlined in formal documents like Frequently Asked Questions (FAQs) that explain the purpose of the community and what standards of behaviour are expected from members. Implicit norms are not formally outlined and can only be learned and understood by observing the day-to-day interactions of established members. Burnett and Bonnici (2003) explain that newly joined members are sometimes advised to lurk in a community before actively joining in so they can learn the implicit rules and avoid sanctions or expulsion from the group for violating those norms. Core members may play an important role in online communities because they are defining members of the community who are responsible for establishing and reinforcing group norms.

In the present study, the presence of a core group meant that a large part of the dataset was generated by a relatively small sub-group 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.

6.4.4.2 Coding framework

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 sub-categories (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.

6.4.4.3 Internet access

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, 2015b). 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 et al., 2011; Selwyn et al., 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.

6.4.4.4 Privacy

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.

6.4.4.5 Onset of support processes

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.

6.5 Conclusions

Social support can play an important role in the well-being 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. Support processes became established almost immediately, similar to what might happen in a face-to-face self-help group. Forum messages 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 struggles, 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.

Chapter 7: Study 3 – A longitudinal analysis of word use within a newly-created CRPS online forum

Abstract

Most research into online support communities has used a retrospective and cross-sectional approach to look at overall forum activity, rather than investigating the experiences of individual members. Many individuals use these communities for extended periods of time, so there is an urgent need for longitudinal research. This study longitudinally examines the use of health words, self- and other-oriented messages, positive and negative words, and the number of replies received using four case studies in the Bath CRPS forum. Results showed that there was considerable variation in the words used over time and across participants. Health words were used in a variety of different contexts. There may be a link between self- and other-oriented messages and support providing activities, and pronoun use might not be a valid way of distinguishing between self- and other-oriented messages. Two distinct patterns were observed in the use of positive and negative words, and may provide a way of identifying individuals who might benefit from additional support.

7.1 Introduction

7.1.1 Retrospective and longitudinal analysis

To date, the majority of research that has examined the content of messages posted to online support communities has adopted a retrospective and cross-sectional approach (for a review of the methods used, see Chen, 2014). That is to say, most datasets used for message analysis have been created through the identification of relevant conversational threads using either a random sampling strategy (e.g. Attard & Coulson, 2012), by selecting messages that were posted over a particular number of days (e.g. Gavin, Rodham, & Poyer, 2008), or by selecting a specific number of

threads (e.g. Malik & Coulson, 2011) or messages (e.g. Rodham, Gavin, Lewis, St. Denis, & Bandalli, 2013). As a result, the data captures the messages posted by a cross-section of online community members. This approach typically involves analysing threads or messages to look at overall forum activity, without examining the experiences of individual members or looking at changes that occur over time (e.g. Attard & Coulson, 2012; Malik & Coulson, 2008b; Mo & Coulson, 2008).

Individuals often use online support communities over extended periods of time (Coulson, 2013; van Uden-Kraan et al., 2009) and their experiences are unlikely to remain static, so there is an urgent need for longitudinal research (Chen, 2014). Longitudinal studies allow researchers to investigate how a phenomenon develops and evolves over time. They can be used to investigate cause-and-effect relationships, and each participant acts as their own control (Salkind, 2006). Very few forum studies have been published that used such a longitudinal design. One notable exception is that of Wen, McTavish, Kreps, Wise, and Gustafson (2011), who analysed all messages posted by a single participant during the 13-month period from the point of diagnosis of breast cancer until her death. The aim was to explore patterns of message posting in relation to disease trajectory. Unfortunately this pioneering study had a number of limitations: notably the participant was arbitrarily chosen, there were no inclusion or exclusion criteria, and it is difficult to generalise from a single non-representative participant.

Researchers may feel uncertain about how to design longitudinal studies (Ployhart & Vandenberg, 2010), and at present there are no established guidelines or techniques for analysing forum messages longitudinally. Therefore, this chapter will use a new longitudinal technique outlined in Section 7.2.3 to analyse forum messages using case studies with a view to yielding new insights into the phenomena of interest.

7.1.2 Linguistic analysis

While looking at forum engagement (Chapter 5) together with the onset of support processes and type of social support that members received (Chapter 6) in the Bath CRPS forum, it was noted that there were differences in the support-providing behaviour of members and also the number of replies received, with some individuals receiving more replies than others. Forums are a text-based method of communication where the absence of social cues means that members rely solely on words to form impressions of each other, build relationships and convey their experiences (Walther, 1996). Consequently, a linguistic analysis of the words used by forum members, the context in which words are used, and how word use changes over time, might provide an insight into support-providing behaviour and the number of replies received.

Linguistic Inquiry and Word Count (LIWC) is a software package that uses special dictionaries to analyse text files by calculating how many words fall into 80 psychologically-important word categories, such as pronouns, verbs, positive and negative emotion words, and cognitive words (Tausczik & Pennebaker, 2010). Even though online support communities are inherently text-based with members communicating exclusively through words, only a small number of studies have conducted a linguistic analysis of the messages posted within these communities. In these studies, it appears that researchers typically look at the percentage of words that fall within each category without considering the context in which those words are used (e.g. Han et al., 2008; Owen, Klapow, Roth, & Tucker, 2004; Shaw, Jeong Yeob Han, Hawkins, McTavish, & Gustafson, 2008). However, the context in which words are used may be important and could change both over time and across participants.

7.1.2.1 Self- and other-oriented messages

Fuglestad et al. (2012) proposed that the motivations for using a forum can be either self-oriented or other-oriented: self-oriented motivations refer to using the forum to gain benefits for oneself, while other-oriented motivations refer to learning about or benefitting other individuals. They found that other-oriented motives predicted basic engagement such as returning to the site, logging in, connecting with others and answering questions (Fuglestad et al., 2012).

In an online support community for women with breast cancer, Shaw et al. (2008) used personal pronouns[6] to distinguish between self- and other-oriented messages. They found that self-oriented messages were associated with higher levels of negative emotions, indicating that individuals who dwell on their own personal difficulties may experience greater negative emotions by focussing on themselves instead of others (Shaw et al., 2008).

Little is known about self- and other-oriented communication in CRPS online support communities. Additionally, it is uncertain whether self- and other-oriented messages reflect a fixed trait that remains stable over time, or if changes occur over time in how individuals use self- and other-oriented messages. For example, messages may become more self-oriented or other-oriented according to changes in their health status.

7.1.2.2 Positive and negative emotions

The use of words expressing positive and negative emotions may also be important in online support communities. Positive emotions are thought to play an important role in health and well-being, and can help individuals to '*bounce back*' from negative

[6] First-person pronouns refer to the speaker (I, we), second-person refers to the person being addressed (you), third-person refers to other parties (he, she, they).

emotional experiences by using humour, relaxation and optimistic thinking to help them cope (Tugade, Fredrickson, & Feldman Barrett, 2004). When writing about personal experiences, individuals who use a high number of positive-emotion words together with a moderate number of negative-emotion words appear to derive the greatest benefit (Pennebaker, Mayne, & Francis, 1997). Using too few negative-emotion words may indicate that the individual has difficulty labelling their feelings or is repressing them, while too many words could suggest that they are dwelling upon negative emotions without finding closure (Pennebaker & Seagal, 1999).

Han et al. (2008) investigated how the use of positive and negative words predict health outcomes in an online support community for women with breast cancer. They found that using more negative words predicted greater health-related concerns at four-month follow-up, but using more positive words did not predict lower health-related concerns at follow-up. The combined use of positive and negative words produced the greatest benefit to individuals, indicating that this may be an effective coping strategy for women with breast cancer.

To date, little attention has been paid to the role of positive and negative emotion words in online support communities for CRPS, or how this might relate to the provision of social support. Furthermore, as discussed in Chapter 1, CRPS is a condition where the symptoms experienced by the individual can change and fluctuate over time, so a longitudinal analysis of health words and also positive and negative emotion words may provide an insight into how the illness impacts on the individual and their use of online support as their symptoms change.

7.1.2.3 Number of replies

While conducting the analysis for Chapters 5 and 6 of this thesis, it was noted that some forum members appeared to receive more replies than others. The reasons for

this were unclear, but if the use of self- and other-oriented messages influences how individuals engage with forums (Fuglestad et al., 2012) and their expression of emotions (Shaw et al., 2008), and if the use of positive and negative words has an influence on health outcomes (Han et al., 2008; Pennebaker & Seagal, 1999), then these may also influence the number of replies that an individual receives. If these characteristics change over time, then it is also possible that the number of replies received might change over time.

7.1.3 Aims

The research aim for this study is to longitudinally investigate the use of health words, self- and other-oriented messages, positive and negative words, and the number of replies received using four case studies in the Bath CRPS forum.

7.2 Methods

7.2.1 Data collection

The data for this study was collected as part of the Bath CRPS forum described in Chapter 4. This study used 94 forum messages, which comprised all messages posted in the '*Welcome*' and '*Your thoughts and experiences*' boards by the participants described in Section 7.2.2.

7.2.2 Participants

Four participants were selected from the 23 active forum members described in Section 4.2.4 by using the following inclusion criteria.

First, participants needed to have written more than the mean of 9.5 messages per participant (see Section 5.3.2.2) and posted messages on the forum for at least three months, to ensure an adequate number of postings distributed over a sufficient time

period to conduct a longitudinal analysis. The six high frequency posters described in Sections 5.3.2.2 and 6.4.4.1 were the only forum members who fulfilled these criteria.

Second, there needed to be sufficient variation across participants to ensure that each individual made a distinct contribution to the analysis. That is to say, if any potential participants had broadly similar experiences to another individual then the '*extraneous*' participants were excluded. Two participants were excluded using this method, based on the similarity of the content of their messages.

Therefore, the data for this study was derived from four participants, three females and one male.

7.2.3 Analysis

The initial data preparation was carried out as described in Section 4.2.3. To prepare the data for longitudinal analysis, individual postings were put into separate sections according to the username of the participant who wrote them. For each participant, messages were then arranged into date order from the earliest message to the most recent using the timestamp contained in the header information of each message.

Multiple data files were produced for each participant. First, an '*overall*' file was generated that contained all the forum messages written by that individual. Second, a series of '*monthly*' files were generated that contained all the messages written by that individual during each calendar month. The Bath CRPS forum ran for a total of seven months, so the use of monthly time intervals was deemed appropriate to capture any changes or developments that arose over time for each participant. These files were all saved as plain text files (.TXT format) and only contained the message body for each posting, with headers, signature lines and other information removed. Spelling and grammatical mistakes were corrected as recommended in the LIWC 2007 manual

(Pennebaker, Booth, & Francis, 2007), by using the inbuilt spell checker in Microsoft Word 2010 to find and correct these mistakes. Linguistic Inquiry and Word Count (LIWC 2007) (Tausczik & Pennebaker, 2010) was used to conduct the linguistic analysis of these files. The number of replies that each message received was calculated using an Excel spreadsheet.

7.2.4 Ethical considerations

The ethical issues for this study are identical to those described in Section 5.2.4.

7.3 Results

In the following analysis, comparisons between participants refer to comparisons between the four case study participants, not comparisons between all 23 forum members. All quoted extracts are reproduced verbatim with the original spelling and grammar used by participants, to ensure that their voices are heard in their own words.

Table 7 shows the percentage of personal pronouns, percentage of emotion words, percentage of health words, the number of messages posted and the percentage of messages that received a reply for each participant during each month of the study. These figures will be examined in the case studies described below.

Table 7: Longitudinal linguistic analysis.

	Personal pronoun words				*Emotion words*				*Replies*	
	Personal pronouns	*First-person*	*Second-person*	*Third-person*	*Emotion words*	*Positive emotions*	*Negative emotions*	*Health words*	*Messages posted*	*Percentage of replies*
Case study 1										
Overall	6.84%	6.52%	0.16%	0.16%	5.55%	1.85%	3.70%	4.10%	12	33.33%
Month 1	6.81%	6.70%	0.11%	0.00%	6.15%	1.65%	4.51%	5.05%	5	40.00%
Month 2	7.53%	6.45%	0.00%	1.08%	2.15%	2.15%	0.00%	0.00%	3	0.00%
Month 3	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	n/a
Month 4	6.67%	5.84%	0.42%	0.42%	4.58%	2.50%	2.08%	2.08%	4	50.00%
Case study 2										
Overall	11.70%	8.29%	2.22%	1.18%	6.29%	4.40%	1.89%	2.07%	25	64.00%
Month 1	11.41%	8.69%	1.23%	1.50%	5.79%	3.86%	1.93%	2.81%	9	77.78%
Month 2	11.52%	8.68%	2.63%	0.20%	6.87%	4.85%	2.02%	1.62%	4	75.00%
Month 3	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	n/a
Month 4	11.59%	6.83%	3.33%	1.43%	6.03%	3.81%	2.22%	2.06%	6	33.33%
Month 5	10.51%	7.00%	3.50%	0.00%	7.39%	5.84%	1.56%	0.39%	4	25.00%
Month 6	16.02%	11.60%	1.66%	2.76%	7.18%	6.63%	0.55%	1.10%	2	50.00%
Case study 3										
Overall	8.46%	6.77%	0.55%	1.14%	5.15%	3.01%	2.07%	1.93%	25	80.00%
Month 1	7.45%	6.53%	0.16%	0.78%	5.38%	3.16%	2.23%	2.17%	16	81.25%
Month 2	8.68%	6.16%	0.00%	2.52%	4.76%	2.52%	1.68%	2.24%	4	75.00%
Month 3	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	n/a
Month 4	11.93%	9.79%	0.61%	1.53%	4.59%	3.06%	1.53%	1.83%	2	100.00%
Month 5	11.43%	5.71%	4.08%	1.63%	3.67%	1.22%	2.45%	0.00%	2	50.00%
Month 6	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	n/a
Month 7	8.82%	5.88%	2.94%	0.00%	11.76%	11.76%	0.00%	0.00%	1	100.00%
Case study 4										
Overall	10.62%	8.99%	0.58%	1.05%	4.72%	2.21%	2.00%	1.97%	32	62.50%
Month 1	10.21%	8.33%	0.70%	1.18%	5.05%	2.96%	2.10%	1.99%	21	61.90%
Month 2	11.06%	9.05%	0.50%	1.51%	2.51%	1.51%	1.01%	2.51%	2	50.00%
Month 3	11.11%	11.11%	0.00%	0.00%	11.11%	11.11%	0.00%	0.00%	1	100.00%
Month 4	13.36%	12.44%	0.46%	0.46%	3.69%	2.30%	1.38%	2.30%	4	75.00%
Month 5	10.74%	9.68%	0.30%	0.76%	4.69%	2.42%	2.27%	1.66%	4	50.00%

7.3.1 Case study 1

Participant 1 was a 45 year-old female who posted forum messages for four months between June and September, posting 12 messages in total.

7.3.1.1 Health words

This individual used more health-related words in her postings than the other participants. Overall, 4.10% of words in her postings were health-related, which is nearly double the percentage of health-related words used by other participants. The number of health-related words that she used also changed over time, where 5.05% of her words were health-related in month 1 compared with 2.08% in month 4.

It appears that this participant used more health-related words than the other participants because of her complicated medical status. In her postings, she described suffering from multiple illnesses that exacerbated each other, as illustrated in the following quote:

> "*the CRPS aggrivates and flares up all the others, and vica versa, so the spondylosis aggrivates the crps, and the crps makes the pain of the spondylosis worse, and the endometriosis makes the crps flare, and crps makes the swelling and pain from the endo worse, and the endo and crps make the menieres worse.. like a never ending roller coaster ride it is*" (Message 4, 9-Jun-2012).

Her messages posted during month 1 contained a higher proportion of health-related words because she spent a lot of time describing how she was diagnosed with CRPS, the symptoms that she experienced, and problems she was having with medications:

> "*Ive stopped taking the baclofen as its not working for me anymore, the valium helps but doesnt stop the pain anymore like it used to, i came off gabapentin as it just made me throw up all the time, Im on paracetamol and codeine, doesnt*

help much though, Im on vit D calichew, and mebevarine for the IBS Im getting, but not much else at the moment" (Message 3, 9-Jun-2012).

Later messages focussed less on medical issues and more on her financial difficulties due to living on social security benefits, being ineligible for grants to adapt or modernise her home, and whether individuals with CRPS should be able to self-refer themselves for treatment:

"*we need a paradyme shift on the needs and rights of crps patients, that they can self refer and get access to therapies such as hydro, hospital gym, and supported alternative therapies to help the condition, as minus these swift interventions it just becomes worse and you can end up losing a foot or a leg*" (Message 10, 7-Sep-2012).

7.3.1.2 Self- and other-oriented communication

This individual used fewer personal pronouns than the other participants. Overall, 6.84% of the words in her postings were personal pronouns. Nearly all of these were first-person pronouns, and she used very few second- or third-person pronouns. There was little change in personal pronoun use over time.

This participant's messages were predominantly self-oriented. She used the forum to talk primarily about her personal circumstances, by asking questions and requesting advice. She rarely posted '*social*' messages to get to know other individuals on a personal level or ask about their lives and experiences, and she rarely provided support to others. For example, she posted the following message about her forgetfulness and enquired if other individuals had similar difficulties, which sadly did not receive any replies:

"*Does anyone else here get terrible brain fog and forget stuff, like leaving the dinner in the oven for 2 hours and continually burning food due to forgetting its cooking or loosing track of time. and losing paperwork and forgetting pay bills and forgetting your phone number, a pin number, and birthdays and what day of the week it is etc. Mine is getting very bad.*" (Message 5, 10-Jun-2012).

7.3.1.3 Positive and negative emotions

This individual used a similar number of emotion words to the other participants, with 5.55% of her words expressing some form of emotion. She expressed more negative emotions than positive emotions. This pattern changed over time, with positive emotions increasing slightly each month and negative emotions falling.

Her messages tended to have a negative and pessimistic tone, where she used the forum to vent her frustrations by '*sounding off*' to others who have experienced similar difficulties, instead of worrying loved ones who might find it difficult to relate to these issues in face-to-face conversations. In the following quote, she powerfully expresses her disappointment and frustration about not being eligible for help to modernise her home:

"*I cant get any adaptations done nor an inside toilet where its warm and not damp unless I take out a loan against my home as council say im not disabled enough for a facilities grant. I told them shuv it, im not taking a loan when Im on benefits and already in debt*" (Message 7, 5-Jul-2012).

Later messages expressed similar sentiments but were phrased in a less negative way, which may indicate that she found it helpful to vent her feelings on the forum:

"*I cant even get a disabled facilities grant to help me have a disabled bath installed and an inside toilet. Because I have a wet room shower I dont meet the*

criteria, and yet soaking in hot water helps the pain and oedema in my legs" (Message 11, 7-Sep-2012).

7.3.1.4 Replies received

This individual received fewer replies than the other participants, with only 33.33% of her messages receiving a reply from other members. There was little change in the pattern of replies over time. This lower number of replies compared with other participants may have been due to the complicated nature of her medical condition, which could have made it difficult for others to provide the help and support that she needed over the Internet.

7.3.2 Case study 2

Participant 2 was a female (age unknown) who posted forum messages for six months between June and November, posting 25 messages in total. She was a volunteer moderator on the forum.

7.3.2.1 Health words

2.07% of the words in her postings were health-related. The percentage of health-related words that she used appeared to fall over time, where 2.81% of words were health-related in month 1 compared with 1.1% in month 6.

Like participant 1, it appears that her earlier messages used more health-related words because they described how she was diagnosed with CRPS, her experiences with various healthcare professionals and the treatment they provided, and also the experiences of other people she knew who were living with CRPS. The following quote is typical of these messages, and describes her experience of trying to do hydrotherapy while on holiday:

> "*I find hydrotherapy really helps and so much easier to do exercises in the water than on land. A few years ago whilst on holiday I used the hotel swimming pool it was cooler than hydrotherapy and I was only able to manage a few minutes before the pain was so bad and I struggled to get out of the water. My foot went purple and swelled and took several days for the pain to ease. I learnt to test the water temperature before entering a swimming pool.*" (Message 8, 20-Jun-2012).

Later messages used health-related words to provide help and support to other forum members. This is illustrated in the following message, which was posted in reply to a newly joined member who requested advice about what to do after a pain consultant dismissively told her to "*get over it*":

> "*After five years of pain I can understand how frustrating it was to hear from a pain consultant that he had seen people in more pain how unhelpful! You need to be taken seriously . […] have you been given desensitisation work to do on your leg and foot?. If not I will post up some help. Even though you have not been given physio help I would suggest that you keep your foot as mobile as you can. Have you access to a hydrotherapy pool?*" (Message 16, 9-Sep-2012).

7.3.2.2 Self- and other-oriented communication

This individual used more personal pronouns than any other participant. Overall, 11.70% of the words in her postings were personal pronouns. She used just over twice as many first-person pronouns as second- or third-person pronouns. There was little change in personal pronoun use over time.

This participant's messages were predominantly other-oriented. Although she often talked about her own experiences, she rarely used the forum to obtain information or

seek support. Instead, her messages focussed on welcoming new members, and providing information, advice, support and encouragement. Often she drew upon her own experiences to empathise with members, demonstrate her understanding of their situation, build relationships, and offer advice. For example, she posted the following reply to a member who announced that she was taking part in a bicycle ride to raise money for scientific research:

> "*This all sounds exciting . It would be really good it you could keep the forum posted about progress for your cycle ride. Sport is a good distraction for people with CRPS even though I do not belong to a sporting club I find exercising in water and swimming beneficial and I enjoy it! Well done [name] on your achievements so far...*" (Message 24, 12-Nov-2012).

7.3.2.3 Positive and negative emotions

6.29% of the words that she wrote expressed some form of emotion. She expressed twice as many positive emotions than negative emotions, and there was little change in this pattern over time.

Regardless of whether she was talking about herself or other people, her messages tended to be positive, supportive and encouraging. For example, when talking about disability aids that members found helpful, she posted the following message about her colourful, folding walking sticks:

> "*Of course they do not help me walk better than my NHS chrome ones but they make me feel better. They are a good conversation subject and people stop me in the street and tell me how they like them. I chose folding sticks because I now try to walk with one stick but I have my spare stick in my back pack on my back if I get tired or if I feel I need the extra support.*" (Message 25, 23-Nov-2012).

7.3.2.4 Replies received

Out of the 25 forum messages that she posted, 64.00% of them received at least one reply from another member. The number of replies received appeared to fall over time, with at least 75.00% of her messages posted in months 1 and 2 receiving a reply, compared with 50.00% or fewer messages in her latter months. This pattern may have arisen because of her role as a moderator. Her earlier messages involved introducing herself, building relationships and talking about her experiences, which typically attracted further responses from other members. However, her later messages often involved answering questions and providing support, and hence replies were not always needed.

7.3.3 Case study 3

Participant 3 was a 54 year-old male who posted forum messages for seven months between June and December, posting 25 messages in total.

7.3.3.1 Health words

This individual used fewer health-related words in his postings than any other participant. Overall, 1.93% of the words used in his postings were health-related. The percentage of health-related words that he used appeared to fall over time, where more than 2.00% of words were health-related during months 1 and 2, compared with no health-related words from month 5 onwards.

In his earlier messages, he provided a detailed description of his medical history and how he came to be diagnosed with CRPS, made preparations to attend a music festival, talked about his mixed experiences of using spas for hydrotherapy, and read scientific papers to learn as much as possible about CRPS:

> "*I only reading up on anatomy & physiology which is taking my red cross training a few steps further along with medical papers such as pain society newsletters and the abstracts, it is so annoying when you cannot get to the full papers Alright I do admit I am concentrating on the nervous system and the brain.*" (Message 9, 18-Jun-2012).

In a later message, this individual described how he used this research to devise a way of treating his own condition, which he then recommended to another member who was having similar difficulties to him and who had described herself as being "at a bit of a dead end":

> "*I understand how you are feeling. I have CRPS in both lower legs and feet. I have hd it since 2004. Until Jan 2012 it was controlled by a spinal cord stimulator which was removed in April. In June I was admitted into hospital as I kept having falls when I tried to transfer to my wheelchair. Despite this I was not getting anywhere then after reading all the info on the methods that [hospital] used I decided to treat myself. I started by lying in a bath having bought a laser thermometer off ebay about £8, I would measure the temperature of my legs(affected areas) and run a bath to that temperature, and slowly immerse myself. Once adjusted to the water, I then slowly warmed the water and just exercised by moving my ankle slowly. after a few sessions I started going to a spa, again measuring the water temperature to make sure it wasn't too cold. I then started to exercise by walking on crutches, the first days 3 steps, second 4 and so on. I can't promise that the pain goes completely but the swelling goes which makes it easier to move […]. But if you take things one step at a time it can be done.*" (Message 21, 11-Sep-2012).

7.3.3.2 Self- and other-oriented communication

Overall, 8.46% of the words used in his postings were personal pronouns, most of which were first-person pronouns. The only notable change over time was an increase in pronoun use during months 4 and 5.

This participant posted a mixture of self- and other-oriented messages. Whereas messages posted during his earlier months involved introducing himself, asking questions and gathering scientific information, messages posted during months 4 and 5 focussed on providing advice, support and encouragement to other members. For example, when a member described the sense of freedom that she got from her new electric wheelchair, which she said was "*an enabler not disabler*", he related this to his own experiences of using a wheelchair:

> "*I guess I have come to accept the accessibility problems, but must admit to when I go into a shop that has clothing on racks that have aisles that are too narrow for the wheelchair, making my own gangways usually leaving piles of clothes on the floor behind me. When staff pull me on it , which is rare I just point out politely that if they complied with access regulations I wouldn't need to do it. […] a lot of [buildings] have bells for the disabled but I find this more frustrating if you don't really know what you want. But can be fun if you get the right assistant as some don't like to be beaten and will bring half the shop to the door. Keep your chin up and remember you can now go further and faster than your daughters and you know your a parent when your kids get embarrassed. Just remember the times when they embarrassed you when they were younger.*" (Message 24, 20-Oct-2012).

7.3.3.3 Positive and negative emotions

5.15% of the words that he wrote expressed some form of emotion. He expressed around 50% more positive emotions than negative emotions, and there was little change in this pattern over time.

He occasionally used the forum to vent his frustrations about issues related to his CRPS, such as the difficulties that he experienced when asking to have his shower room converted into a bathroom, as illustrated in the following extract:

> "*I am so angry at the moment. I have just been told by my occupational therapist that she is unlikely to write to the housing association to ask them to change my wet floor shower room to a bathroom, because I had the conversion done 10years ago and the standard practise for disabilities is a wet floor and shower. God do they not read anything if it is about Complex regional pain syndrome. This is the same woman that gave me a leg lifter that hooks round the foot, when my CRPS is in both lower legs and feet. God help us all! Rant over*" (Message 17, 5-Jul-2012).

Most of his messages focussed on trying to find practical solutions to the difficulties that he faced. For example, the following message describes his preparations for attending a music festival:

> "*I am at a friends house tomorrow building a cage for the front of the wheelchair to protect the legs. The festival site is only 2miles from my house so easy to come home every night and my wife is coming as my carer and she is better than a rottweiller if anyone comes near my legs Other years I have had no problem without a cage but had scs then, so taking no risks. And festival*

atmosphere takes the mind off the pain, watching all the drunks." (Message 13, 19-Jun-2012).

7.3.3.4 Replies received

Out of the 25 forum messages that he posted, 80.00% of them received at least one reply from another member. There was little change in the pattern of replies over time. Other members asked him questions to learn more about his illness and experiences, they supported his efforts to learn more about CRPS, and they expressed an interest in his ideas about how to treat his own illness.

7.3.4 Case study 4

Participant 4 was a 22 year-old female who posted forum messages for five months between June and October, posting 32 messages in total.

7.3.4.1 Health words

1.97% of the words in her postings were health-related. There appeared to be little change over time in the percentage of health-related words that she used.

It appears that this individual used a similar percentage of health-related words throughout her time on the forum because she worked in a medical-related field. Sometimes she drew on her work-related experiences to provide information, advice and support to other members. For example, during a discussion about searching for health-related information on the Internet, she posted the following message:

"*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. I mean that in the nicest possible way and only from experience of dealing with patients in many different departments, especially rheumatology. My theory is, if it hasn't been published by a reputable source (such as Arthritis Research UK, NHS ect...) then there is a*

potential for the info to be unresearched or not evidenced based. I found that out when I read the symptoms list on some RSD/CRPS site a few weeks ago, it had many symptoms I'd never seen elsewhere for CRPS and when I asked for references for where the info came from, they weren't able to give me any and was told that some of the symptoms were actually from other conditions! So just be careful with what you're reading into CRPS and other condition for that matter." (Message 10, 18-Jun-2012).

Other messages talked about her own health difficulties, medications, and the impact of CRPS on her career. When asked how she managed her career alongside the challenges of living with CRPS, she posted the following reply:

"*I guess I just get on with it. I've had CRPS in my foot for about 7 years now (I think, must be something like that by now) but I've never had crutches etc... and I'm not disabled. When I finally got my diagnosis and started using my foot more normally again my symptoms improved a lot! I also live by 'It hurts if I don't use it, it hurts if I do but I may as well use it and have something to show for my pain'.*" (Message 32, 16-Oct-2012).

7.3.4.2 Self and other-oriented communication

Overall, 10.62% of the words used in her postings were personal pronouns, most of which were first-person pronouns. There was little change in personal pronoun use over time, but there was a change in her use of self- and other-oriented messages over time.

During months 1 and 2 she posted a mixture of both self- and other-oriented messages. Self-oriented messages talked about her CRPS symptoms, her reasons for not taking any medications, and difficulties sleeping, while other-oriented messages provided

support and advice to other members, and also involved taking part in '*social*' discussions. For example, during a discussion about disability aids she talked about buying shoes:

> "*Does having lots of pairs of shoes count? Before I was diagnosed I kinda used my foot as an excuse to buy new shoes/trainers to try find ones that were comfy/I could get my foot in...So it was part practicality, part '[I am] a shoe-a-holic'...Oh and I used to have different socks too that I found more comfy but I've lost them over the years but could be done with some again... That's about it for me really, don't really have any aids or adaptation.*" (Message 16, 26-Jun-2012).

The messages posted during months 3, 4 and 5 were primarily self-oriented. A change in her circumstances meant that she had to start taking medications for her CRPS symptoms, which adversely affected her sleep cycle and also impacted on her career, as this message explains:

> "*Getting fed up with the awful sleep pattern my current medication is causing and also being back at university for 6 weeks (2, almost 3 weeks down only 3 more to go...) is hard. […] I hate going to uni as it means I have to drive which aggravates my foot, it also costs a fortune which I really can't afford at the moment and it's often totally boring and feels slightly pointless being there...Ah well, needs must.*" (Message 29, 4-Oct-2012).

7.3.4.3 Positive and negative emotions

4.72% of the words that she wrote expressed some form of emotion. She expressed more positive emotions than negative emotions, and there was little change in this pattern over time.

Her expression of emotions may have been linked to the change that occurred in her health status. Her self-orientated messages were often used to vent and express her frustrations about the difficulty that she had sleeping, as illustrated in the previous section, while her other-orientated messages were typically encouraging and supportive.

7.3.4.4 Replies received

Out of the 32 forum messages that she posted, 62.50% of them received at least one reply from another member. There was little change in the pattern of replies over time. Other members responded positively to the support and advice that she offered, and they were encouraging and supportive of the difficulties that she experienced when her health status changed.

7.4 Discussion

The aim of this longitudinal study was to investigate the use of health words, self- and other-oriented messages, positive and negative words, and the number of replies received using four case studies in the Bath CRPS forum.

7.4.1 Health words

Health words were used in a variety of different contexts. Participants used health words to describe their personal CRPS-related circumstances and difficulties, to provide information, support and advice to others, to discuss medications, disability aids, scientific research and ways of self-managing CRPS, and to talk about wider social issues such as eligibility for social security benefits.

There were changes over time in both the number of health words used and the context in which they were used, with different participants using health words in different ways. Participant 1 initially used health words to describe her complex

medical situation, and later used fewer health words when talking about wider social issues like disability benefits. Participant 2 initially used them to describe her experiences of CRPS, and later used them while supporting others. Participant 3 initially used them to learn more about CRPS, and later used them to support others and describe how he self-managed his condition. Participant 4 showed the opposite pattern to participant 2, by initially using health words to support others, and later using them to describe her own difficulties following a change in her health condition.

The use of health words appeared to be unrelated to the number of replies received, but the context in which they were used may have had an impact on replies. For example, participant 1 used twice as many health words as other case study participants and received the fewest replies, because her complicated medical status made it difficult for others to provide the help and support that she needed through the forum. Participants 2, 3 and 4 used fewer health words but received more replies. The greater number of replies might not have been because they used fewer health words, but because their support needs appeared to be less complicated and made them better suited to receiving help through the forum.

7.4.2 Self- and other-oriented communication

The distinction between self- and other-oriented messages may have both practical and methodological implications.

On a practical level, it appears that there may be a link between an individual's health status, their use of self- or other-oriented messages, and support-providing activities on the forum. Participant 1 had a complex medical history with multiple diagnoses that made it difficult to self-manage her CRPS, and her messages were predominantly self-oriented. She rarely provided support to others or posted '*social*' messages to

build relationships with other members. Similarly, when participant 4's health status changed making it more difficult for her to self-manage her illness, her messages became primarily self-oriented. She still answered questions about herself when others enquired about her well-being, but she no longer posted supportive replies to help other individuals. In contrast, participants 2 and 3 used a mixture of self- and other-oriented messages, posted '*social*' messages, and provided support, advice and encouragement to others throughout their time on the forum.

These findings indicate that individuals may not engage fully with other members when they are at their most distressed. They still used the forum to talk about their difficulties and vent their frustrations, and they often continued to receive supportive replies from other members, but they were less likely to reciprocate by providing support to others. Even though they were distressed and did not engage as fully as the other case study participants, these individuals still appeared to benefit from using the forum by interacting with others, recognising that they are not alone, receiving support, and venting their frustrations.

Methodologically, personal pronouns have been used in the literature to classify messages as being self- or other-oriented (e.g. Shaw et al., 2008). However, the present findings indicate that pronoun use might not be a valid way of distinguishing between self- and other-oriented messages.

Participant 1's messages were predominantly self-oriented, she used fewer personal pronouns than the other participants, and nearly all of her pronouns were first-person pronouns. Participant 2's messages were predominantly other-oriented with little change over time, but she still used twice as many first-person pronouns as second- and third-person pronouns. Participant 3 posted a mixture of self- and other-oriented messages, and his pronoun use increased over time when he posted messages

providing support and encouragement to others. Participant 4 initially posted a mixture of self- and other-oriented messages, her later messages were predominantly self-oriented, but there was little change over time in her use of personal pronouns. This suggests that there was no direct relationship between pronoun use and whether the individual posted self- or other-oriented messages, which may mean that it is necessary to examine the content of messages in order to classify them as self- or other-oriented.

Additionally, the distinction between self- and other-oriented messages does not appear to form a dichotomy in the way that was originally conceived by Fuglestad et al. (2012). Self- and other-oriented forum use varied over time, across participants and within messages. Some messages were self-oriented, some were other-oriented, and some messages fell simultaneously into both categories. Some participants had a consistent posting style over time, for example participant 1's messages were typically self-oriented and participant 2's messages were usually other-oriented. Other participants had posting styles that changed over time, for example participant 4 initially posted a mixture of self- and other-oriented messages but later messages were predominantly self-oriented. It appears that the use of self- and other-oriented messages can change as each individual's needs and motivations change.

The use of self- and other-oriented messages appeared to be unrelated to the number of replies received. For example, most of the messages by participant 1 and the later messages by participant 4 were self-oriented, and participant 1 received fewer replies than participant 4. Likewise, participants 2 and 4 received a similar percentage of replies despite participant 2 predominantly posting other-oriented messages and participant 4 posting a mixture of self- and other-oriented messages.

7.4.3 Positive and negative emotions

Two distinct patterns emerged in the use of positive and negative emotion words, neither of which showed any change over time. First, three participants used a higher percentage of positive words together with a moderate percentage of negative words. Second, one participant used the opposite pattern with a lower percentage of positive words together with a higher percentage of negative words.

The messages posted by participants 2, 3 and 4 all used a higher percentage of positive words together with a moderate percentage of negative words. In the literature, individuals who used this combination of positive and negative words were found to have the best health outcomes in a four-month follow-up (Han et al., 2008), suggesting that this pattern of word use may be indicative of individuals using the forum to help them develop a more effective range of coping strategies to help them manage their illness (Pennebaker & Seagal, 1999).

There are a number of possible explanations for how this may benefit individuals. First, Tugade et al. (2004) suggested that positive emotions may provide individuals with the resilience to help them '*bounce back*' from negative events by using humour, relaxation and optimistic thinking to help them cope with their situation. Second, these individuals all posted supportive messages that were intended to provide help to other forum members. The helper-therapy principle (Section 2.4.5) describes how helping others can have a beneficial effect on the individual, which may indicate that individuals who post a greater number of positive messages are more likely to help both others and themselves. Third, taking part in online support communities could potentially lead to improved illness self-management by contributing to the CRPS '*four pillars of intervention*', as described in Section 6.4.3.

The messages posted by participant 1 used a lower percentage of positive words together with a higher percentage of negative words. In the literature, this pattern of word use has been associated with poorer health outcomes, including higher rates of illness and increased reporting of symptoms (Pennebaker et al., 1997). The Bath CRPS project did not measure health outcomes, but it does appear that participant 1 had a more complicated health condition than the other case study participants. The content of her messages indicated that she was diagnosed with multiple illnesses, where the symptoms of each condition could exacerbate the difficulties associated with her other conditions. It appears that participant 1 may have benefitted from using the forum because, over time, there was an increase in the percentage of positive words used by this individual together with a reduction in the percentage of negative words used.

The number of positive and negative words used may have implications for clinicians. If an online support community is used as part of a wider health intervention to support the needs of individuals living with CRPS, then the percentage of positive and negative words could potentially be used to identify individuals who might benefit from additional help and support. For example, if an individual uses more negative words than positive words then this may indicate that they are not currently receiving the support that they need to manage their illness effectively. Similarly, if an individual's pattern of positive and negative words changes over time, then this might be indicative of a change in their circumstances that might trigger the need for additional support.

7.4.4 Limitations and future research

Calculating the number of replies that were received by each message was not straight forward. As discussed in Section 4.2.1, threads in the Bath CRPS forum had a

relatively simple structure that only allowed members to post replies to the discussion thread rather than responding to a specific message. For some messages, replies could be identified by looking for quoted extracts from the original posting, or by looking at the context of replies to see if they were answering a specific question from a previous message. However, a small number of messages were more ambiguous and there was a degree of uncertainty in identifying which message they were replying to (Petrovčič et al., 2012). In future studies, the number of replies could be calculated more accurately by conducting research with forums that have a hierarchical threading structure where each message can receive its own clearly identifiable replies.

This study had a very small sample size consisting of only four participants. This arose as a consequence of the longitudinal approach that was used, such that most forum members did not post a sufficient number of messages to analyse their data longitudinally. It appears that only one previous forum study has used a longitudinal design, by Wen et al. (2011), which only had a single participant. This study demonstrates that it is possible to conduct in-depth quantitative and qualitative longitudinal research with multiple participants by adopting a case study approach. However, the relatively small number of participants makes it difficult to assess how closely the data from these individuals reflects the experiences of all forum members, or how well the results can be generalised to other forums.

7.5 Conclusions

There is an urgent need for longitudinal research into online support communities, and the longitudinal case study approach described in this study may provide new insights into phenomena of interest. Health words were used in a variety of different contexts, and may impact the number of replies received depending on the complexity of that person's problems and the ease of providing appropriate support over the Internet. The

use of self- or other-oriented messages appears to reflect the individual's health status and support-providing behaviour. Distressed individuals appeared to use more self-oriented messages, engaged less fully with other members, but still continued to benefit from using the forum. The number of positive and negative words used by each individual may be important for clinicians, and could potentially be used to identify individuals who might benefit from additional support.

Chapter 8: Overall discussion

Abstract

This final chapter brings together the results of all three empirical studies and examines them in the context of existing literature and theories. After a brief summary of the main issues raised in the literature review and empirical chapters, the findings will be considered in terms of how online support processes develop in relation to the launch of a new online support community, and the provision of social support for CRPS within an online support community.

8.1 Introduction

Chapter 1 reviewed the literature on pain and Complex Regional Pain Syndrome, examining what CRPS is, how it is diagnosed and treated, and the difficulties that individuals face when living with this debilitating illness. Little is known about what causes CRPS and why some cases recover spontaneously while others become chronic. CRPS is difficult to treat and it cannot be cured, so it is vital for individuals to learn how to self-manage the illness. Treatment focusses on the '*four pillars of intervention*', which consist of education, pain relief, rehabilitation and psychological intervention. Having the right kind of social support appears to be crucial, but individuals may become socially isolated and withdrawn because of the unpleasant nature of their symptoms. The Internet presents opportunities for individuals to interact with others through social media such as online support communities, where they can exchange social support, information and advice. This means that social support received over the Internet may be particularly beneficial to individuals with CRPS. Despite the potential importance of online social support for CRPS, little is known about how individuals with CRPS use online support communities, what kind of social support they receive, or how this might potentially contribute to the '*four pillars of intervention*'.

Chapter 2 examined the literature on online support communities, looking at what the Internet is and who uses it, health-related Internet use, online support communities and who uses them, their advantages and disadvantages, what people talk about, and also theoretical approaches to online support. The Internet can potentially be accessed from anywhere in the world, yet there are widespread inequalities in who uses the Internet and how they use it. Even in countries with high levels of Internet use, Internet user typologies indicate that most people can still be categorised as being either non-users or occasional-users. There are so many health-related resources on the Internet that it has been described as being the world's largest medical library. Individuals can take part in online support communities, search for health information, interact with healthcare professionals, book appointments, order prescriptions, access their medical records, and use social media to follow the health status of others. Online support communities allow individuals to interact with others who have the same health condition and have been through similar experiences. Despite the prevalence of chronic illness in society, surprisingly few people use online support communities. Most research has focussed on established communities, so little is known about what happens when a new online support community is launched and how support processes get established. Additionally, very little research has investigated online support communities for CRPS.

Chapter 3 looked at the Internet as a research tool, examining the advantages and disadvantages of online data collection, and practical and ethical issues related to message analysis studies. Chapter 4 introduced the Bath CRPS project, which involved launching a brand new discussion forum for individuals living with CRPS. Chapters 1 and 2 highlighted several gaps in the current understanding of online support communities for CRPS, therefore the aim of this thesis was to address some of these gaps and expand current knowledge about how individuals with CRPS use and benefit from online support.

The Bath CRPS forum presented a unique opportunity to investigate how a new online support community becomes established, and also online social support for CRPS.

The findings in Chapter 5 described how individuals engaged with the forum, with a particular focus on membership growth, header analysis and introductory messages. Chapter 6 reported how support processes got started in the forum, what kind of social support individuals received, and how this contributes to the '*four pillars of intervention*'. Chapter 7 used a new research method to longitudinally analyse forum messages, and investigated support-providing behaviour and the number of replies received.

8.2 The development of support processes when a new online support community is launched

Online support communities have attracted considerable research attention (for recent reviews, see Chen, 2014; Malinen, 2015; Mo, Malik, & Coulson, 2009), with the majority of studies focussing on established communities that have existed for quite some time. Few studies have looked at new online support communities, and consequently little is known about the development of online support processes when a community is launched or how these communities become established. However, Iriberri and Leroy (2009) provide a framework that can be used to understand what happens when a new community is launched. They studied the lifecycle of discussion forums and other types of online support community, and identified five key stages in their evolution: inception, creation, growth, maturity and death. The decisions that are made during each of these stages have an important impact on how the community is shaped and developed.

Inception involves having an idea for a new community that the individual would like to create. Coulson and Shaw (2013) reported that individuals may have many different reasons for deciding to create a new online support community. Sometimes it is because they cannot find any existing communities for that particular condition, to help people

stay in contact between face-to-face support group meetings, to inform and educate people about treatment options, because they are a specialist in that condition or they have access to an appropriate expert who can answer questions and provide advice, to help people feel less isolated, and because they want to help others. Moreover, creating a new community can have an empowering effect on the individual. Coulson and Shaw (2013) indicated that creating an online support community can help the individual to grow, learn and deal with their own experiences through helping others. This is consistent with the helper-therapy principle (Riessman, 1997), discussed in Section 2.4.5, which shows how helping others can have a beneficial effect on the individual.

Creation refers to the process of setting up the new community and putting it on the Internet for others to use. Section 2.3.2 discusses the different types of online support community that can be created. In addition to creating a community dedicated to a particular health condition, the individual must decide if they want it to be a single-function community (i.e. a standalone community) or a comprehensive community (i.e. one that includes additional services like reference materials or decision-making tools) (Finfgeld, 2000), and what technological platform to use. For example, online support communities can take the form of discussion forums (e.g. Attard & Coulson, 2012), Usenet newsgroups (e.g. Loader et al., 2002), e-mail ListServs (e.g. Cummings et al., 2002) and chat rooms (e.g. Letourneau et al., 2012). Forums are the most prevalent type of online support community (Barak et al., 2008) and there are a number of platforms that can be used to create forums, each with different features and different styles of user interface, so the individual must think carefully about what characteristics they would like their community to have and what features are likely to be important to the target membership group (Iriberri & Leroy, 2009). Alternatively, the online support community

could be created within a popular social networking site such as Facebook (e.g. Bender et al., 2011; Greene et al., 2011).

Growth is the third of Iriberri and Leroy (2009)'s five stages. When the new online support community has been created and launched, members will hopefully find the community, join it and start posting messages to ask questions, request information, get to know each other, enforce rules and provide support. The growth of a new community is particularly important for its success, because the community needs to achieve a '*critical mass*' of members for discussions to become self-sustaining (Jones et al., 2004; McCarty, 1992). Section 8.2.1 examines membership growth, while Section 8.2.2 looks at how support processes become established.

Maturity occurs when the community becomes established after successfully achieving a critical mass of both members and content. While the owner focusses on sustainability and the long-term success of the community, individual members develop trusting and long-lasting relationships. At the same time, new members continue to join and provide fresh topics for discussion. The Bath CRPS forum failed to reach this stage, because the hacking incident (Section 4.2.2) prevented the forum from developing normally and consequently it did not achieve the required critical mass of members.

Death is the final stage in the lifecycle of online support communities, and occurs when members stop using the community. If individuals lose interest in the community, or if there is no longer enough high-quality content to sustain discussions, then activity levels will fall and the forum dies. As discussed in Section 4.2.2, the Bath CRPS forum died after the hacking incident took place, which severely disrupted communication within the forum. A total of two threads were created and eleven messages posted during the final five months after the forum was hacked, but this did not allow the forum to regain enough

momentum to continue. This highlights how fragile online support communities can be, and demonstrates how a newly launched community can erode as quickly as it evolves.

8.2.1 Membership growth

According to Iriberri and Leroy (2009), the growth of an online support community plays an important part in its subsequent success or failure. As discussed in Section 5.1.2, little is known about how membership levels grow when a new forum is launched. It was anticipated that membership growth could take a number of distinct patterns, such as linear growth, exponential growth or burst growth.

Linear growth could occur if a similar number of new members join each month, leading to a consistent and predictable rate of growth. For example, if ten new members joined every month then there would be an overall total of twenty members at the end of the second month, and thirty members after the third month.

Exponential growth might occur if there was a snowball effect where an ever-increasing number of new members join each month. This could happen if each new member told two other people about the community, and each of those told two more people, and so on. For example, if ten new members joined in the first month and each of them encouraged two more people to join, then there would be an overall total of thirty members at the end of the second month, and seventy members after the third month.

Burst growth may happen if some months have a sudden increase in newly joined members while other months have little change in membership levels. For example, the first and second months might both have an overall total of ten members, but a marketing campaign carried out by members might lead to a '*burst*' of new members joining in the third month, which increases the overall total to twenty members.

In the Bath CRPS forum, the results in Section 5.3.1 and the analysis in Section 5.4.1 indicated that membership growth occurred in bursts. Specifically, the majority of forum growth took place during two distinct bursts, the first of which occurred in June and the second in September and October. Each burst saw a relatively large number of new members join the forum compared with the background level of growth that was observed in the other months. These bursts coincided with targeted recruitment campaigns launched by the Bath CRPS team to increase awareness of the forum and encourage new members to join. This is consistent with how people tend to discover online support communities, with research indicating that most individuals discover communities by chance while searching for health information on the Internet, through word-of-mouth from family members or patient organisations, or through marketing campaigns carried out by the community (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008). In the Bath CRPS forum each marketing campaign led to a burst of new members joining, while the background growth may have been associated with people discovering the forum by chance or through word-of-mouth.

This appears to be the first study to examine membership growth in this way, so this is a new finding in the literature. It suggests that publicity campaigns may play an important role in the success of some newly launched online support communities, by making potential new members aware of the community and its intended target audience. However, this finding should be treated tentatively for two reasons. First, it is only based on data from a single forum that had 23 participants, which ultimately failed to achieve the required critical mass for discussions to become self-sustaining. In effect, this is an example of membership growth in a forum that died without achieving Iriberri and Leroy's maturity stage. Other online support communities may have different growth patterns to the one observed in Chapter 5. Second, as explained in Sections 5.2.3 and

5.4.4.1, membership growth was calculated by examining the month when each member posted their first message. There is a possibility that some members may join a community and spend time lurking before posting any messages (Colvin et al., 2004; Winzelberg, 1997), so future studies may need to examine membership growth by looking at each individual's date of registration rather than the date when their first message was posted.

8.2.2 How support processes get started

As discussed in Section 6.1.1, the growth stage described by Iriberri and Leroy (2009) appears to be critically important for how support processes become established when a new online support community is launched. During this stage members will start posting messages to ask questions and exchange social support, but little is known about exactly how support processes get started. There are two possibilities for how this might happen: a gradual build-up of support, or an immediate launch of support.

Gradual build-up of support: When a new community is launched and there are only a small number of members, the support content of messages could initially be quite low. The first members who join might tentatively post messages to exchange support, even though there are few other people for them to interact with. As additional new members join, there will be more people who can post replies and provide support. This could produce a snowball effect where support processes slowly build and develop over time alongside the membership growth of the community.

Immediate launch of support: Alternatively, following the launch of a new community, the first interactions to take place might contain high levels of social support irrespective of the number of members who are present for them to interact with. This is similar to what might happen in face-to-face support groups, where individuals meet for the first time and begin supporting one another straight away.

In the Bath CRPS forum, the results in Section 6.3.1 and the analysis in Section 6.4.1 indicated that support processes became established almost immediately. Specifically, a total of 84 messages were posted during the first month and 83.3% of those messages contained at least one type of social support, even though the forum only had a small number of members (seven participants) during that month. The provision of social support arose almost immediately, similar to what might happen in face-to-face support groups, with forum members actively posting messages to introduce themselves, build relationships, answer questions, discuss their experiences, and exchange social support.

This appears to be the first study to examine how support processes become established when a new online support community is launched, so this is a new finding in the literature. It suggests that support processes can start almost immediately even when there are only a small number of members for individuals to interact with. The large number of messages posted during the first month combined with the small number of members may indicate that the provision of social support depends upon how individuals engage with the online support community, rather than membership growth and the number of people who are using it. Future research will need to continue examining and refining the concept of engagement, to identify what aspects of engagement are important for support processes to become established.

8.3 Online social support for CRPS

8.3.1 Trigger events

Individuals may have many different reasons for joining an online support community, and sometimes they have more than one reason for joining. Coulson (2013) described 14 reasons why individuals join these communities, including wanting to find others who are in a similar situation (80.7% of respondents), to learn about their condition (66.3%), sharing their experiences (65.1%), sharing information with others (58.6%), seeking

emotional support (57.0%), seeking advice (56.2%), offering support to others (54.2%), and because they wanted to ask a question about their condition (51.4%).

Other studies have obtained similar findings. For example, Ridings and Gefen (2004) reported that individuals join to obtain or exchange social support (38.2% of respondents), to obtain information and share insights with others (38.2%) and for friendship (17.1%). The reasons for joining can also reflect the advantages and benefits of online support community membership, such as being able to access support at any time, alleviating feelings of isolation, and using the community to discuss coping strategies or feel better about themselves (Coulson, 2013; Coulson & Knibb, 2007).

According to LaCoursiere (2001)'s theory of online social support, discussed in Section 2.4.2, the decision to join an online support community may be triggered by an initiating event. Specifically, a change in the individual's health status or their perceived health may prompt them to join. That is to say, if they have just been diagnosed with a condition or if they are worried about their health, then this may trigger the need for information or support and lead to them joining an online support community.

In the Bath CRPS forum, the results in Section 5.3.3 and the analysis in Section 5.4.3 indicate that individuals can have a diverse range of reasons for joining an online support community, and sometimes they can have more than one reason for joining. Sections 5.3.3.2 and 5.4.3.2 discussed the precipitating event that led to the individual being diagnosed with CRPS. These precipitating events took many different forms: some individuals were diagnosed following surgery for another condition, a road traffic accident, a fractured or broken bone, a sporting injury or direct impact to the limb, or by developing the condition spontaneously. One individual's precipitating event was uncertain because she had so many medical complications that it was difficult to establish what caused her to develop CRPS.

LaCoursiere (2001) suggested that a change in health status might prompt the individual to seek online support, but changing patterns of Internet use may mean that this is no longer the case. There have been notable changes in household Internet usage since LaCoursiere's theory was published in 2001. According to Office for National Statistics (2015a), the number of UK households with Internet access increased from 36% in 2001 to 86% in 2015, and the percentage of adults who use the Internet every day increased from 35% in 2006 to 78% in 2015. As the Internet becomes increasingly embedded in daily life (Leung, 2008), it appears that LaCoursiere (2001)'s concept of trigger events may need to be revised.

Rather than joining the Bath CRPS forum because of a change in their health status or perceived health, Sections 5.3.3.6 and 5.4.3.6 revealed that individuals were triggered to join the forum by a wider range of motives: in addition to seeking support and advice, individuals were also motivated to join because of wanting to contribute to scientific research, or because they hoped to meet others with CRPS from the same geographical area. This is consistent with previous findings regarding the diverse range of motivations that individuals have joining online support communities (Coulson, 2013; Coulson & Knibb, 2007; Ridings & Gefen, 2004). Further research may be needed to confirm whether these trigger events are associated with the decision to join other types of online support community, and if they also apply when individuals decide to post health-related information on social networking sites such as Facebook.

8.3.2 Engagement

After the trigger events described in Section 8.3.1 prompt the individual to join an online support community, they will engage with the community to receive social support, information and advice. The type of social support received, and how this contributes to the CRPS '*four pillars of intervention*', will be discussed in Sections 8.3.4 and 8.3.5.

As discussed in Section 5.1.1, engagement has typically been conceptualised as a unitary concept in the literature, and has been used in different ways by different researchers. For example, some researchers have looked at how frequently an individual uses a community (van Uden-Kraan, Drossaert, Taal, Lebrun, et al., 2008; Zrebiec & Jacobson, 2001) or the amount of time that they spend online during an average session (Boberg et al., 1995; Gustafson et al., 1992), while others have described engagement using arguably rudimentary terms such as '*posters*' (i.e. individuals who post messages) and '*lurkers*' (i.e. individuals who only read messages) (Mo & Coulson, 2010a; Nonnecke & Preece, 2000; see also Malinen, 2015).

This thesis has argued that engagement is a multi-dimensional construct with at least three components: the number of people who join, how they introduce themselves, and how they use the forum. The first of these components, the number of people who join (i.e. membership growth), was examined in Section 8.2.1 to look at growth patterns and why this aspect of engagement is important to the success or failure of newly launched communities. The other components are examined in Sections 8.3.2.1 and 8.3.2.2.

Widening the conceptualisation of engagement into a multi-dimensional construct appears to be a new finding in the literature, and may more accurately reflect the many nuances and complexities of how individuals engage with online support communities. The components described here are unlikely to represent a full and comprehensive account of how individuals engage with these communities, so it is anticipated that future research may continue to expand this conceptualisation by identifying other components of engagement.

8.3.2.1 Introductory messages

How individuals introduce themselves in their first message can be crucially important for how they subsequently engage with that community. Barak et al. (2008) explain that

existing members could respond in a number of different ways: they might be welcoming and supportive, they could be critical and off-putting, or they could completely ignore the message. Whether the new member receives a friendly, unfriendly or mixed response will reflect the culture of the community, its group norms, and the dynamics and personalities of existing members. In turn, this will influence the newly joined member's perception of that community, whether they want to continue being a member, how they will integrate themselves into the group, and how they will engage with that community.

In the Bath CRPS forum, the results in Section 5.3.3 and the analysis in Section 5.4.3 indicated that these introductory messages took the form of '*disease stories*' (Armstrong et al., 2012) with six themes: personal details, precipitating event, symptoms, treatment, living with CRPS, and reasons for joining.

Personal details provided socio-demographic information such as their name, age and location, and may have helped individuals form relationships by compensating for the lack of visual cues when interacting using text-based communication on the Internet (Coulson & Knibb, 2007; Finfgeld, 2000; White & Dorman, 2001). Precipitating events referred to how they were diagnosed, and were examined in Section 8.3.1. Their descriptions of symptoms, treatment regimens and their experience of living with CRPS helped to establish their legitimacy and authority within the forum (Galegher et al., 1998), that is to say, it demonstrated that they should be accepted as members and that their opinions are valid because they are living with CRPS just like the existing members. Reasons for joining were examined in Section 8.3.1.

The six themes that form the structure of these introductory messages appear to be a new finding in the literature, and help to provide a more detailed understanding of why an individual's first message can have such an important impact on how they subsequently engage with an online support community. In a similar way to how early introductory

messages can '*set the tone*' for how other newly joined members introduce themselves (Rodham, Gavin, Coulson, et al., 2013), it appears that how an individual introduces him or herself can '*set the tone*' for being accepted as a member and continuing to engage with that community. Further research is needed to establish whether introductory messages posted in other types of online support community also have the same structure. For example, the structure of these introductions might be unique to each online support community or unique to individuals with a particular health condition, and it might vary depending upon whether a forum is '*open*' or '*closed*'. Additionally, research needs to investigate if and how individuals introduce themselves when using other social media outlets such as social networking sites for health-related purposes, to see if they also use a similar structure.

8.3.2.2 Forum activity

Another important component of engagement is how the individual uses the online support community. As explained in Section 5.1.3, forum messages consist of header information and the message body (Petrovčič et al., 2012). Message headers provide a range of useful information like the username of the individual who wrote it and the timestamp showing when the message was posted, all of which can be analysed to investigate how an online support community is used (Boberg et al., 1995; Eichhorn, 2008; Galegher et al., 1998; Pfeil et al., 2011; Winzelberg, 1997). The message body contains the textual content of the message, which can also be useful if the researcher is interested in looking at the number of sentences or words in each message (Weinberg & Schmale, 1996; Winzelberg, 1997).

In the Bath CRPS forum, the results in Section 5.3.2 and the analysis in Section 5.4.2 revealed how participants used the forum. They posted a mean of 1.0 (2.1) messages per day, a mean of 9.5 (12.9) messages per participant, created a mean of 0.7 (1.1) discussion

threads per participant, and received a mean of 7.5 (10.4) replies per thread. The forum was used at all times of the day, evening and night.

This appears to be a new finding in the literature. While online support communities for other health conditions have been studied in this way, this is the first time that this approach has been used to examine an online support community for CRPS. The findings may be particularly important because one possible explanation for this pattern of results may indicate that diffusion of responsibility could occur within these communities, which will be examined further in Section 8.3.3.

8.3.3 Diffusion of responsibility

Diffusion of responsibility (Darley & Latané, 1968) is a phenomenon that occurs when the presence of multiple people leads to a reduced likelihood of any particular individual providing help. As Darley and Latané (1968) explain, if only one individual is present when an incident occurs then any responsibility to intervene is focussed solely on that individual. They can choose to intervene, or alternatively they might ignore the situation because they feel concerned about their personal safety, do not have the skills to help, or would prefer not to get involved. However, if more than one individual is present then the responsibility for intervening becomes shared (i.e. diffused) among the group. Under these circumstances, the individual may not know if another person has already intervened, or if anybody else present has knowledge and skills that would make them better helpers. This may increase the likelihood of non-intervention, such that nobody intervenes. The potential blame for not helping becomes shared among so many people that the blame to any particular individual may be non-existent.

In health psychology, this can have implications for the likelihood of receiving help. In an elaborate laboratory-based study that involved taking part in discussions using an intercom, a victim was heard having an epileptic fit. If the participant thought they were

the only person to hear the emergency then 85% responded by raising the alarm before the fit ended, but if they thought four others could also hear the emergency then only 31% raised the alarm (Darley & Latané, 1968). This '*bystander apathy*' effect has proved to be remarkably consistent across a wide range of studies and contexts (Latané & Nida, 1981), and can play an important role in the likelihood of receiving help during a genuine medical emergency. For example, the likelihood of a bystander providing cardiopulmonary resuscitation (CPR) following an out-of-hospital cardiac arrest decreases when there are more people present (Vaillancourt, Stiell, & Wells, 2008). Similarly, the presence of four or more bystanders reduces the likelihood of somebody telephoning for an ambulance after witnessing a drug overdose (Tobin, Davey, & Latkin, 2005).

Diffusion of responsibility has been found to occur on the Internet. E-mailing help requests to multiple recipients reduces both the number of replies received and the helpfulness of those replies compared with e-mailing a single person (Barron & Yechiam, 2002). Similarly, sending e-mail help requests to a ListServ that forwards e-mails to all subscribers is three times less likely to produce a reply than e-mailing a single person, with larger ListServs being less likely to help than smaller ones (Yechiam & Barron, 2003). Similar to what happens in face-to-face situations, it appears that the likelihood of receiving a reply on the Internet falls as the number of recipients increases.

Comparison of the header analysis data from the Bath CRPS forum with equivalent data from other online support communities suggests that forums with a smaller number of members appear to produce more replies than those with a larger number of members. Specifically, the Bath CRPS forum had 23 members and produced 7.5 replies per thread (see Section 5.4.2), an eating disorders group with 70 members produced 6.4 replies per thread (Winzelberg, 1997), and groups for arthritis (16,000 members), attention deficits

(18,000 members) and depression (23,000 members) produced 3.5 replies per thread (Galegher et al., 1998). One possible explanation for this is that diffusion of responsibility may also occur within forums.

Yechiam and Barron (2003) propose two explanations for why this might occur. First, online support communities with a larger number of members may produce a greater volume of messages per day, requiring an increased time commitment to read all the messages and compose replies. If an individual only has a limited amount of time available then this may restrict how many replies they can write, making them less likely to reply to any particular message. Second, knowing that there is a large number of members may lead to a perception that replying is less important, because the responsibility for replying becomes shared (i.e. diffused) among the group. In effect, the individual may '*learn*' that they do not need to reply, leading to a reduced likelihood of help being provided.

This may be an important finding because it appears to be the first study to indicate that diffusion of responsibility might also occur within online support communities. As suggested in Section 5.4.4.2, further research may be needed to investigate this more fully. One approach would be to collect data from a wide range of online support communities regarding the number of members and mean number of replies per thread to see if a negative relationship can be confirmed, where a greater number of members leads to a smaller number of replies. If a negative relationship does not exist then this would reject diffusion of responsibility as a possible explanation for these findings. Additionally, it may be possible to use a questionnaire survey to compare attitudes towards posting behaviour in large and small communities to see if any differences arise that are consistent with diffusion of responsibility.

8.3.4 Type of social support received

Section 2.4.1 examines definitions of social support and why it is important for health and well-being. It is especially important for individuals with CRPS to have the right kind of social support to help them self-manage the condition (Feldman et al., 1999; Rodham, McCabe, et al., 2013). Unfortunately, individuals living with this illness often have a greatly reduced social network through which they can obtain support (Rodham et al., 2009), and they can also experience difficulties taking part in social and recreational activities due to the unpleasant nature of their symptoms (Galer et al., 2000). The growing popularity of the Internet has provided new opportunities for individuals living with a chronic health condition such as CRPS to receive social support by engaging with online support communities.

The results in Section 6.3.2 and the analysis in Section 6.4.2 examined what kind of social support individuals received by using the Bath CRPS forum. Emotional support was found to be the most frequent (present in 73.8% of postings), followed by informational support (34.8%), esteem support (31.2%), network support (7.2%) and tangible aid (2.3%).

This appears to be a new finding in the literature, and is the first study to look at the social support content of messages in a CRPS online support community. These results are consistent with optimal matching theory (Cutrona & Suhr, 1994) discussed in Section 2.4.3, and also the uses and gratifications model (Grace-Farfaglia et al., 2006; Lee & Hawkins, 2010) discussed in Section 2.4.4.

Optimal matching theory (Cutrona & Suhr, 1994) proposes that certain types of support will be more beneficial to the individual depending upon the nature of the problem that they are experiencing. Emotional support was particularly important to individuals because it helped them to cope with the uncontrollable aspects of living with CRPS, while

informational support was also important because it helped to provide individuals with the resources they needed to overcome controllable problems.

The uses and gratifications model (Grace-Farfaglia et al., 2006; Lee & Hawkins, 2010) proposes that individuals have unmet needs, and that they use mass media outlets such as the Internet to fulfil those needs. It appears that participants who used the Bath CRPS forum may have had informational and emotional support needs that were not being fulfilled by their existing resources, and hence they used the forum to gratify those needs (Lee & Hawkins, 2010).

One of the most important findings to arise from this is how online support communities have the potential to contribute to the CRPS '*four pillars of intervention*', which will be discussed in Section 8.3.5.

8.3.5 Contribution to the four pillars of intervention

As discussed in Section 1.2.4.5, CRPS treatment requires an interdisciplinary approach based on the '*four pillars of intervention*', which represent the '*gold standard*' for CRPS treatment (Goebel et al., 2012; Turner-Stokes & Goebel, 2011). The '*four pillars*' focus on education, pain relief, rehabilitation and psychological interventions. Education helps the individual to learn more about CRPS, treatment options, how to manage the illness, and how their behaviour can affect pain levels. Pain relief helps to control pain levels and overcome sleep problems. Rehabilitation helps to restore functioning in the affected limb, and can also assist the individual with work-related difficulties. Psychological interventions help the individual to stay positive, develop coping skills and address other issues that may contribute to maladaptive behaviour.

The results in Section 6.3.2 and the analysis in Section 6.4.3 indicate that participating in online support communities may help individuals to manage their CRPS by contributing to the '*four pillars of intervention*', as described below.

Educational needs: Informational support received through the forum appeared to serve a range of educational purposes. It provided factual information about CRPS together with practical advice about living with CRPS and how to minimise the disease's impact on daily activities. The forum also acted as a venue for discussing treatment options, setting goals, and reviewing their progress. Participants also used esteem support to compliment each other on their achievements.

Pain relief: Informational and emotional support messages were used to discuss medications, invasive treatments and pain management courses, with individuals talking in detail about their experiences of various pain control techniques and whether they found them helpful or unhelpful. This helped individuals to learn more about potential options for pain control, and also gave them a realistic appraisal of how effective each option was likely to be based on the experiences of others.

Rehabilitation: Informational, emotional and esteem support messages provided help with physical rehabilitation, with individuals exchanging information and advice about exercise, desensitization and disability aids that helped them to restore and maintain normal functioning. They also used emotional support for vocational rehabilitation, discussing the challenges in their working lives and the difficulties that they faced if they were unable to work.

Psychological interventions: Individuals used informational, emotional and esteem support messages to discuss coping strategies, negative problems, and the importance of remaining positive by focussing on the important things in life. Additionally, network

support reminded individuals that they are not alone in their experiences, which may have also helped to improve the psychological well-being of participants.

This appears to be a new finding in the literature, and provides a framework for understanding how individuals with CRPS might benefit from engaging with online support communities. Further research may be needed to investigate how participating in these communities may contribute to the '*four pillars of intervention*'. In particular, an online survey questionnaire could be used to investigate individuals' self-reported accounts of whether these communities help them to feel more educated about CRPS, better supported, more positive about their illness, and leads to them having greater feelings of control and empowerment.

8.3.6 Support-providing behaviour and replies received

Chapter 7 introduced a new longitudinal methodology that uses case studies to analyse forum messages over time (Section 7.2.3). Longitudinal research appears to be under-used in the literature, and the case study approach described in this thesis could potentially be applied to any type of online social media messages that are posted with a username and timestamp. It could also be used with a range of qualitative techniques including thematic analysis (Braun & Clarke, 2006) and content analysis (Elo & Kyngäs, 2008; Pfeil & Zaphiris, 2010), to obtain new insights into phenomena of interest.

As explained in Section 7.1.2, the text-based nature of online support communities and the absence of social cues on the Internet means that members have to rely solely on written communication to form impressions of each other, build relationships and convey their experiences (Walther, 1996). Linguistic analysis was used to investigate support-providing behaviour and the number of replies that individuals receive by looking at the words used by forum members, the context in which words are used, and how word use changes over time.

The results in Section 7.3 and analysis in Section 7.4 appear to have a number of important implications, which appear to be new findings in the literature. First, the context in which health words are used may have an impact on the number of replies that individuals receive while using these communities, with some individuals having a complicated health status that makes it more difficult for others to provide help and support over the Internet.

Second, the use of self- and other-oriented messages may be linked to their health status and also support-providing activities. In particular, it appears that individuals who are at their most distressed may not engage as fully with other members. Messages posted by distressed individuals appear to be self-oriented, and they used the forum to vent their frustrations and talk about their difficulties. They often received supportive replies from other members but were less likely to reciprocate by providing support to others. Additionally, although personal pronouns words have been used in the literature to distinguish between self- and other-oriented messages (e.g. Shaw et al., 2008), the analysis in Section 7.4.2 indicates that this might not be a valid way of categorising messages as being self- and other-oriented. Instead, it appears to be necessary to examine the content of messages to classify them as self- or other-oriented, and that some messages can be self-oriented, some can be other-oriented, and some can simultaneously fall into both of these categories.

Third, it appears that the number of positive and negative words used in forum messages may have implications for clinicians, particularly if an online support community is being used as part of a wider programme to provide help and support to individuals who are living with CRPS. The analysis in Section 7.4.3 suggests that it might be possible to identify individuals who would benefit from additional support by looking at the ratio of positive-to-negative words in their messages. Specifically, if an individual uses more

negative words than positive words then this may indicate that they are experiencing difficulties with successfully self-managing their illness, and could benefit from interventions to provide additional support.

8.4 Limitations and future research

There are a number of potential limitations to the research presented in this thesis. First, the analysis is based on a forum that only had 23 active members, which was badly disrupted by a hacking incident and failed to develop into a true online community. Additionally this data was collected from a '*closed*' forum that offered a greater level of privacy than what is available in '*open*' forums. Consequently, although these findings have produced new insights into online social support for CRPS, this body of research is based on a very small dataset. It is uncertain whether the participants are representative of all individuals living with CRPS, or if the findings can be generalised to other online support communities.

Second, it emerged that some participants were using other social media outlets such as Facebook for health-related purposes alongside the Bath CRPS forum. For example, some members were using Facebook to interact with each other in addition to exchanging messages through the forum, and this meant that forum messages would sometimes go unanswered because a similar message had been posted and answered on Facebook. It is unclear whether this behaviour also occurs in other online support communities, but the growing popularity of social networking sites like Facebook and Twitter may mean that the simultaneous use of multiple social media outlets could be commonplace when seeking health-related information, support and advice, because posting a message on multiple sites may increase the likelihood of receiving a helpful reply. Future research will need to examine whether individuals have preferences for certain types of social media when accessing online support, and how this affects engagement and the type of

support received. For example, it may be more convenient to access Facebook from a mobile phone or tablet computer rather than using a PC's web browser to use forum-based online support communities.

Third, this analysis was conducted using a qualitative approach, and no inferential tests were carried out. This means that it is not possible to infer causality or statistical significance regarding any of the findings that emerged from these studies. Future research will be needed to confirm many of these results, for example, to determine if there is a statistically significant relationship between the ratio of positive-and-negative words used by an individual and them needing additional support to self-manage CRPS.

Fourth, it appears that socio-demographic statistics might not reveal the full picture regarding who uses online support communities. As discussed in Section 2.1.2, research indicates that there are several different types of Internet user, reflecting qualitatively different patterns in how individuals use the Internet (Brandtzæg et al., 2011; Selwyn et al., 2005). Little is known about how these different types of Internet user engage with online support communities. It is possible that instrumental or advanced Internet users might be more likely to join online support communities 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. It might be possible for future research to produce a typology of online support community users, reflecting different patterns of use along similar lines to typologies of Internet users (Brandtzæg et al., 2011) and social networking website users (Brandtzæg & Heim, 2011).

8.5 Conclusions

This thesis examined the development of online support processes following the launch of a new online support community for CRPS, and the provision of social support within that community. Support processes began almost immediately when the forum was

launched, similar to what might happen in a face-to-face support group, and membership growth was closely linked to the promotional campaigns used to increase awareness of the forum. Engagement is conceived as being a multi-dimensional construct with at least three components (membership growth, how they use the forum, and how they introduce themselves). Introductory messages took the form of '*disease stories*' that can '*set the tone*' for being accepted as a member and continuing to engage with the community. There is a possibility that diffusion of responsibility may occur within forums, whereby an increased number of members may reduce the likelihood of receiving a reply. Social support received on the Internet may play an important role in the CRPS '*four pillars of intervention*', and help individuals to self-manage their illness. There is an urgent need for longitudinal research into online support communities, and the case study approach used in this thesis may produce important new insights. The use of health words appears to be unrelated to the number of replies received, the use of self- and other-oriented messages may be linked to health status and support-providing activities, and the ratio of positive-to-negative words could potentially be used to identify individuals who might benefit from additional support.

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