Members' Experiences of a Neuromuscular Disorder Online Support Group

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Abstract

Introduction: Neuromuscular disorders (NMDs) cause wasting and weakening of muscles. People affected by NMDs and their carers can experience a number of adverse psychosocial consequences, which can be exacerbated by the rare nature of many of these disorders. This makes access to medical information, timely diagnoses, supportive care and peer support difficult. Options for receiving peer support are increasing through the development of online support groups (OSGs) for people affected by NMDs.

Aims: This thesis examined the role of a new OSG in facilitating online peer support for people affected by NMDs and their carers. This was carried out using two distinct, but inter-related, studies. The first study examined the various ways in which members used the message board facility. The second of these studies accessed members' personal experiences of using this OSG.

Methods: In order to examine how members used this new OSG, the first study involved an inductive thematic analysis of OSG message postings. Message postings from the first five months of this OSG's existence (n=1,914) were analysed, so as to identify the main thematic content of members' discussions.

The second study accessed participants' personal accounts of their OSG experiences. Semi-structured interviews were conducted with six OSG members and were analysed using Interpretative Phenomenological Analysis (IPA). This interview element examined the context through which members decided to use the group, factors that contributed to their continued use of the group, and the personal impact of participation.

Results: The OSG message postings analysis demonstrated how members created a sense of community spirit by establishing common ground through disclosing personal information, searching for connections with people with similar illness experiences or interests, welcoming new members, and sharing aspirations for the development of a resourceful community. Experiences, emotional reactions and support were shared in relation to: delayed diagnosis; symptom interpretation; illness

management and progression; and the sense of isolation incurred when managing a rare disorder. The board was also used to discuss societal and political issues pertaining to living with an NMD and methods of raising awareness of such conditions.

The results of the interview study showed the valued connection that the OSG gave participants to similar others, in a friendly, non-pressurised environment. Members especially valued the reassurance of knowing that they were not alone in coping with their often-rare condition. The group provided participants with an understanding audience: a rare experience for a group whose condition is not widely known or understood. The information exchanged on the OSG was appreciated due to its specificity in dealing with NMDs. The board was also considered an important platform for raising awareness of NMD-related issues. The gratifying experience of helping other NMD sufferers was highlighted as a key theme.

Participants also felt that the OSG was not without its limitations. Difficulties in relating to other people (because of varying disability levels, different disease progression histories, and different views on politics and other interests) influenced participants' levels of interaction and the perceived benefits of the group. Less common concerns for the group – but important for some individuals – were privacy concerns in using a publicly accessible group and difficulty navigating through the message postings.

Conclusions: This thesis provides a novel, in-depth insight into how people used a new OSG for NMDs, and the personal impact of participating in such a group. Analyses of message posting and interview data highlight the vital psychosocial support provided by the OSG, especially given the rarity of many of these conditions. However, it was found that some obstacles to support are inherent in the OSG itself, tempering assessments of the impact of its use.

Acknowledgements

Contents

Glossary of Terms and Abbreviations

Administrator: An administrator of an online community has overall responsibility for managing the technical aspects of the group. They are often involved in establishing the online support group (OSG), and setting the rules of participation in the OSG. They may also be responsible for recruiting moderators to help support the everyday management of the group.

Asynchronous communication: Asynchronous communication is a term used to describe communication in which there is no fixed time requirement for responding to others. For example, participants in an online message board can post and respond to messages at a time that suits them. This is in contrast to synchronous or 'real time' communication where all communicating participants must be present at the same time (e.g., in an online chat conversation or a telephone conversation).

BMD: Becker muscular dystrophy

Chat rooms: A chat room is a term used to describe an online space where people can communicate in groups using instant messaging. This allows people to communicate online in groups in 'real time'.

DM: Myotonic dystrophy

DMD: Duchenne muscular dystrophy

Flaming: Flaming is a term used to describe interactions between internet users which are deliberately hostile or aggressive in nature.

IPA: Interpretative phenomenological analysis

LGMD: Limb-girdle muscular dystrophy

LISTSERV: The term listserv refers to a particular brand of electronic mailing list software. An electronic mailing list allows participants to send messages by e-mail to all members of the 'list' at one time.

Lurkers: This term is used to describe people who read messages posted to online communities, but who do not actively contribute to the community by posting messages, or sending e-mails or private messages.

MD: Muscular dystrophy

Message board/forum/bulletin board: A message board, sometimes known as a forum or bulletin board, refers to the space on an online community where members can post messages to which any other online community members can respond asynchronously. Some message boards are private, in that only members who have joined the group can read message postings. Such groups require participants to use a username and password to view the message board. Other groups have publicly accessible message boards and thus anyone outside the community can read messages.

Message thread: A message thread, sometimes abbreviated to a 'thread', refers to a set of messages which are organised under a specific topic heading on a message board or e-mail list.

MG: Myasthenia gravis

Moderator: A moderator is an online community member who has responsibility for the day-to-day running of the community, in terms of overseeing the communication between members. This role involves monitoring the content of messages and may involve organising the direction of message threads. Moderators also often intervene if online interactions become hostile and control unwanted posts on the message board.

NMD: Neuromuscular disorder

Online Support Group (OSG): An online support group (OSG) is an online community where members can discuss issues of common concern. An OSG can be seen as an online alternative to traditional face-to-face self-help groups. The focus of this thesis is on health-related OSGs. Online support groups can either be peer- or professionally-led in nature. The

term online support group in this thesis will refer to peer-led OSGs, unless otherwise stated.

Posters: Posters is the term used to describe members of an online community who actively participate by posting messages to a discussion board.

Private Messaging (PM): A private message, often abbreviated as 'PM', is a message which is sent directly between members of an online community through the online group website. These messages differ from message postings to a discussion board as they are sent in private to one or more members of the group, rather than being visible to the entire group membership.

SMA: Spinal muscular atrophy

Chapter 1: Introduction

1.1 Background

Internet users are increasingly utilising online sources of health-related information. Options for receiving peer support from others with similar health concerns are expanding through the development of online support groups (OSGs), in the form of message boards, e-mail lists and chat groups for people affected by a wide range of health conditions. OSGs are a unique source of support, as members can communicate with each other either synchronously or asynchronously, allowing them to participate at a time of their choosing. OSGs can provide participants with access to a wide variety of people who are affected by similar health concerns, regardless of geographical location. In comparison to face-to-face self-help groups, potential barriers to participation (e.g., transport issues and the time requirement to attend self-help group meetings) are reduced.

Neuromuscular disorders (NMDs) are diseases which cause wasting and weakening of muscles. Many, but not all, of the disorders are inherited. While NMDs is an umbrella term for multiple conditions, there is considerable variety in terms of the clinical features of these conditions, such as age of onset, illness progression and disability severity.

A review of the NMD literature suggests that people affected by NMDs and their carers can experience a number of adverse psychosocial consequences in relation to coping with their conditions. Many NMDs are progressive, which means that individuals may have changing support and information needs over time. The challenge of coping with an NMD can be exacerbated by the often-rare nature of many of these disorders, which can make medical information, timely diagnoses, specific supportive care and peer support difficult to access.

1.2 Research objectives

This thesis broadly aims to examine the role of a new OSG in facilitating peer support for people affected by NMDs and their carers. A specific aim of this research is to examine how members use the message board of this OSG in the early stages of the group's development. A further aim of this thesis is to examine the experience of participation from the perspective of OSG members, specifically in terms of: the context through which members decided to use the OSG; factors which contributed to their continued use of the OSG; and any personal impact of participation.

1.3 Contribution of the study

While there is a growing literature base in relation to the role of OSGs in supporting patients and carers affected by a variety of illnesses, the impact of OSGs in NMDs is under-researched. Indeed, research on the use of OSGs by those with other rare disorders is also limited. This thesis, therefore, serves to fill a void in the literature in terms of understanding the role of online support for people with NMDs and those who care for them.

This research is particularly timely, as it coincided with the development of a new OSG by a charity in the U.K. dedicated to supporting people affected by NMDs. It was this OSG that was used for the research conducted in this study.

1.4 The structure of the thesis

The following eight chapters of this thesis are structured as follows. Chapter 2 presents an overview of NMDs, in order to provide the reader with an understanding of these disorders. It begins by introducing NMDs and describing their prevalence, as well as the physical health impact of living with such conditions. The psychosocial impact of living with NMDs and care-giving for someone with an NMD is then presented. The potential role of social support in facilitating adjustment to NMDs is then discussed, alongside a description of the limited research available on psychosocial support interventions for NMDs.

A review of relevant OSG literature is provided in Chapter 3. This chapter begins with a description of the growth in online health information seeking and introduces OSGs and research on motivating factors for OSG use. Unique features of OSGs as a source of support are also presented. The approaches used to examine the content of online communication are then discussed, alongside key findings. Research on outcomes of OSG participation is then presented, along with a consideration of methodological challenges associated with conducting outcome research in naturally occurring OSGs (i.e., those not specifically designed as part of a research study).

A description of the methodology used in this thesis for the analysis of messages posted to the chosen OSG is contained in Chapter 4. This chapter presents a rationale for this study and the chosen methodology, a discussion of ethical issues pertaining to message postings analysis, and a consideration of how these issues were addressed in this study.

In Chapters 5 to 7, results of the message postings analysis are presented. The results are separated into three over-arching categories, which are presented separately in successive chapters. Chapter 5 ('Connecting and Sharing') contains themes related to how participants introduced themselves on the message board and established a group identity, including how they presented and supported one another in terms of diagnosis experiences. Members' discussions of symptom interpretation, emotional reactions to symptoms, and the support provided in relation to symptom management are presented in Chapter 6 ('An Understanding Audience'). Chapter 7 ('Recognition and Awareness') is concerned with how members discussed living with their condition in terms of the wider societal and political climate.

The final empirical chapter, Chapter 8 ('A Valued Connection'), presents a qualitative interview study that aimed to explore the role of the OSG from the perspective of its members. The rationale for this study and the methodology used are described, before the results of the study are presented within four main thematic categories. The implications of the study are then discussed.

The overall discussion chapter, Chapter 9, gathers together the empirical findings from this thesis and discusses their implications in relation to the wider literature. Directions for future research are presented.

Chapter 2: Neuromuscular Disorders

2.1 Introduction

The focus of this chapter is to firstly describe neuromuscular disorders (NMDs) and provide a brief outline of the prevalence of various NMDs. The physiological impact of such conditions is then introduced, before the psychosocial challenges of living with NMDs are considered, both from the perspective of people who have the condition and their family members or carers. Psychological factors which may affect adjustment to coping with an NMD are then considered. The specific role of social support in coping with NMDs is then discussed. The existing literature on support interventions in NMDs is presented, followed by a brief introduction to the potential role of OSGs in supporting those impacted by NMDs.

2.2 Definition of NMDs

Neuromuscular disorders are conditions which affect nerve control over voluntary muscles in the body, leading to weakening and wasting of muscles (Hilton-Jones, 2011). Many types of NMDs are genetically inherited, while others are acquired. Some conditions are progressively debilitating. Although research is being undertaken to develop potential genetic therapies to treat these conditions, there is currently no cure for these disorders. The focus of current medical treatment is therefore on symptom management and supportive care, such as dealing with respiratory and cardiac complications (Hilton-Jones, 2011).

2.3 Types of NMDs

There is a wide variety of neuromuscular disorders. The most recent version of the gene table of NMDs (Kaplan, 2012) provides a comprehensive list of known monogenic NMDs, i.e., conditions for which the genetic cause is known or at least located on a particular chromosome. These 16 groups of conditions are summarised in Table 1, below:

Groups of NMDs with a known genetic cause
Muscular dystrophies
Congenital muscular dystrophies
Distal myopathies
Congenital myopathies
Other myopathies
Myotonic syndromes
Ion channel muscle diseases
Malignant hyperthermias
Hereditary cardiomyopathies
Metabolic myopathies
Congenital myasthenic syndromes
Spinal muscular atrophies
Hereditary ataxias
Hereditary and sensory neuropathies
Hereditary paraplegias
Other neuromuscular disorders

TABLE 1: GROUPS OF NMDS WITH A KNOWN GENETIC CAUSE

Within each type of NMD described in the above gene table, several different diseases are incorporated under each grouping. For example, different types of muscular dystrophy (MD), which is an umbrella term for a specific group of genetically inherited NMDs (Emery, 2008), are differentiated according to the particular group of muscles affected and by the distribution of muscular weakness.

Although NMDs share common features, there is also huge variation within and between disorders in terms of symptoms, disease onset and progression. For example, similar muscles are affected in both Duchenne MD (DMD) and Becker MD (BMD). However, onset of DMD occurs in early childhood, and death usually occurs during adolescence or early twenties. In contrast, BMD typically develops around the age of twelve, with those affected living to or beyond middle-age (Emery, 2008). The onset and progression of some NMDs can also vary within each specific type of

disease. For example, the onset of facioscapulohumeral MD (FSHMD) and myotonic dystrophy (DM) can vary widely from childhood to adulthood (Emery, 2008).

The symptoms of NMDs are primarily physiological. However, some specific types of NMDs have been associated with an increased risk of various types of cognitive impairment and behavioural difficulties. For example, the frequency of learning difficulties, autism and behavioural problems has been found to be higher for children diagnosed with BMD than in the general population (Young et al., 2008). Similarly, there is evidence of elevated levels of cognitive impairment among people affected by DMD (Mochizuki et al., 2008) and DM (Ekström, Hakenäs-Plate, Tulinius & Wentz, 2009), with issues such as frontal cognitive impairment worsening over time (Sansone et al., 2007). An increased possibility of behavioural and emotional problems among children with DMD has also been found (Polakoff, Morton, Koch & Rios, 1998; Steele et al., 2008). However, in other disorders such as limb-girdle muscular dystrophy and spinal muscular atrophy (SMA), there is no evidence of a higher risk for cognitive impairment or behavioural problems (Miladi, Bourguignon & Hentati, 1999; Laufersweiler-Plass et al., 2003; von Gontard et al., 2002).

It is clear that there is a wide range of conditions incorporated under the umbrella term of NMDs, all of which have varying clinical features and associated prognoses. A full description of the specific features of each type of condition is beyond the remit of the current review. However, these conditions share commonalities, in that they are mainly inherited, progressive conditions, which cause muscular wasting, weakness and problems with motor function.

2.4 Prevalence of NMDs

There is a growing body of epidemiological research into the prevalence of NMDs. Current research suggests that there are approximately 70,000 people in the UK living with an NMD (Pohlschmidt & Meadowcroft, 2010). The prevalence of particular groups of NMDs is detailed in Table 2, adapted from Pohlschmidt and Meadowcroft (2010). This table shows that the most prevalent groups of NMDs are hereditary neuropathies, disorders of the neuromuscular junction, myotonic disorders and

muscular dystrophies (comprising 32%, 14.7%, 13.3% and 12.6% of the total number of people affected by NMDs respectively).

Group of conditions	Patient number in UK	Percentage of total (%)
Hereditary neuropathies	23,000	32
Disorders of the neuromuscular junction	10,500	14.7
Myotonic disorders	9,500	13.3
Muscular dystrophies	8,000-10,000	12.6
Inflammatory and autoimmune neuropathies	6,400	8.9
Myositis	5,000-6,000	7.7
Mitochondrial myopathies	3,500	4.9
Spinal muscular atrophies (SMA)	1,200	1.7
Congenital myopathies	1,000	1.4
Periodic paralysis	900	1.3
Metabolic myopathies	700	1
Distal myopathies	300	0.4
Myositis ossificans progressiva (MOP)	60	0.1
Total number (prevalence)	**70,060-73,060**	**100**

TABLE 2 : PREVALENCE OF SPECIFIC TYPES OF NMD

Another recent study provides data on the prevalence of specific types, rather than groups, of NMDs (Norwood et al., 2009). The most prevalent NMD types reported were hereditary motor and sensory neuropathy (HMSN; prevalence of 40 per 100,000), DM (10.6 per 100,000) and mitochondrial disorders (9.2 per 100,000). The next most prevalent NMDs were dystrophinopathies (including DMD and BMD; 8.46 per 100,000), FSHD (3.95 per 100,000), LGMD (2.27 per 100,000) and SMA (1.87 per 100,000). Less common NMDs included Ulrich MD and Emery-Dreifuss MD, which had a prevalence of less than 1 per 100,000. Due to the low prevalence of a number of these disorders, many NMDs are considered to be rare conditions (Pohlschmidt & Meadowcroft, 2010)

2.5 Physical health impact of NMDs

Despite the wide variety of different NMDs, a number of similarities, in terms of the physical health impact of living with these conditions, can be identified. A number of longitudinal studies have confirmed the progressive nature of many NMDs, in terms of an individual's physical

health. The most common progressive effect is a decline in muscle strength over time (Boström, Nätterlund & Ahlström, 2005; Dahlbom, Ahlström, Barany, Kihlgren & Gunarsson, 1999). Specifically, the progression of these disorders can lead to a decline in the ability to carry out activities of daily living (Boström et al., 2005; Grootenhuis , de Boone & van der Kooi, 2007), a decrease in ambulatory ability (Boström & Alström, 2004; Boström et al., 2005; Nätterlund & Ahlström, 2001; Zebracki & Drotar, 2008), decreased gross and fine motor skills (Grootenhuis et al., 2007), higher levels of fatigue (Boström & Ahlström, 2004) and a deterioration in lung capacity and cardiac health (Dahlbom et al., 1999). Over time, individuals may need to depend more on others for help with a range of activities (Boström & Ahlström, 2004; Nätterlund & Ahlström, 2001).

Severe fatigue has been reported across several types of NMDs, including MD, DM and HMSN type 1 (Kalkman et al., 2005; Schillings et al., 2007). A large scale longitudinal study of 198 participants who had three different types of inherited NMDs (FSHMD, DM and HMSN type 1) found that higher fatigue levels were significantly associated with increased sleep disturbances, lower physical activity level, lower muscle strength and higher levels of pain (Kalkman, Schillings, Zwarts, van Engelen & Belijenberg, 2007). Disordered breathing while sleeping is also a common issue among those affected by NMDs (Mellies et al., 2003).

The association between NMDs and chronic pain is widely evident and has been established using a variety of research methods, including survey studies (Abresch, Carter, Jensen & Kilmer, 2002; Carter et al., 1998; Jensen, Abresch, Carter & McDonald, 2005; Rahbek et al., 2005; Zebracki & Drotar, 2008), qualitative interview studies (e.g., Boström & Ahlström, 2004), clinical case studies (e.g., Bushby, Pollitt, Johnson, Rogers & Chinnery, 1998) and comparative studies with other illnesses (e.g., George, Schneider-Gold, Zier, Reiners & Sommer, 2004). Differences exist in the specific types of pain and the levels of pain experienced by people across differing NMDs (Jensen et al., 2005). While chronic pain is significant in many types of NMDs, there are some exceptions. For example, pain levels among those living with SMA have been shown to be comparable with the general population (Abresch et al., 2002).

2.6 Psychosocial impact

While numerous studies have examined the physically disabling aspects of NMDs, the research literature on patients' own perspectives on their conditions and their emotional well-being is less developed (Piccinni, Falsini & Pizzi, 2004). The emerging research, however, does highlight the negative impact NMDs can have on an individual's quality of life and emotional well-being. The impact of living with an NMD also extends beyond dealing with physical symptoms to the challenges related to the impact of having an often-rare genetic disease. Individuals and families affected by rare conditions are likely to experience a unique type of burden related to difficulties in establishing diagnoses, accessing expert care, encountering a lack of public awareness, and being confronted with the fact that most rare disorders do not have a cure (Schieppati, Henter, Dains & Aperia, 2008).

In the following sections, the psychosocial challenges of living with an NMD are firstly presented, focusing in particular on the challenges people with NMDs may face in terms of social isolation. Research which has attempted to quantify the impact of NMDs on individuals' psychological well-being is then presented, followed by a discussion of research related to coping with an NMD.

2.6.1 Psychosocial challenges of living with an NMD

There are a number of specific psychosocial challenges which individuals with NMDs have to face, related to the implications of living with a rare disease and the often-progressive nature of their conditions. In relation to the inherited nature of many of these conditions, individuals also face a number of specific challenges.

Families affected by NMDs find genetic information difficult to comprehend (Firth, Gardner-Medwin, Hosking & Wilkinson, 1983) and some find it difficult to accurately understand their level of risk for carrier status (Parsons & Clarke, 1993). Qualitative studies have indicated that discussing familial NMD risk can be difficult (Krause-Bachand & Koopman, 2008; Williams & Schutte, 1997). As well as trying to come to terms with understanding the genetic nature of their illness, individuals may also need to deal with feelings of guilt associated with potentially passing on

this illness to their children (Arnold, McEntagart & Younger, 2005; Boström & Ahlström, 2005).

While the options for genetic testing for carrier status are improving over time, there are still both positive and negative aspects of getting tested for both the individual and their family members. Receiving a diagnosis can be beneficial for individuals in terms of managing their illness in the future. However, some people have reported difficulties in disclosing genetic information to their family and to insurance providers (Williams & Schutte, 1997). As highlighted in Boström and Ahlström's (2005) qualitative study, potential carriers can have ambivalent feelings towards being tested as their test results may also reveal inheritance patterns which are significant for other members of the family.

Specific challenges encountered by families of people with NMDs, owing to the progressive nature of many of these conditions, include feelings of loss of control and fear and uncertainty about the future (e.g., Arnold et al., 2005; Boström & Ahlström, 2005; Krause-Bachand & Koopman, 2008). Sufferers have also reported feeling worried about becoming a burden to others as their disease progresses (Sadjadi et al., 2011).

Among those with NMDs who experience changes in their physical appearance due to their illness, some reported experiencing stigma when their illness became more apparent (Arnold et al., 2005; Boström & Ahlström, 2004; Sadjadi et al., 2011). Others reported having to manage people's misconceptions about their symptoms (Krause-Bachand & Koopman, 2008; Sadjadi et al., 2011). Feeling isolated as a result of the progressive nature of their symptoms can be identified as a common experience for people with NMDs (Boström & Ahlström, 2004; Krause-Bachand & Koopman, 2008).

2.6.2 NMDs and psychological well-being

One focus for NMD research over recent years has been the examination of the impact of living with an NMD on quality of life. Quality of life (QoL), as a concept, has many different subjective definitions and interpretations. The World Health Organisation describes QoL as "a broad ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal

beliefs and their relationships to salient features of the environment" (The WHOQOL Group, 1995, p.1405).

The MOS 36-Item Short-Form Health Survey (SF-36; Ware & Sherbourne, 1992), a commonly used multi-dimensional QoL measure, measures QoL in terms of physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/vitality, pain and general health perceptions. Other multi-dimensional measures which have been used in relation to NMDs include the Sickness Impact Profile (Bergner, Bobbitt, Carter & Gilson, 1981), the Nottingham Health Profile (Hunt, McEwan & McKenna, 1985) and, more recently, the Individualised Neuromuscular Quality of Life questionnaire (InQoL; Vincent, Carr, Walburn, Scott & Rose, 2007). All measures relate to an individual's assessment of their functional ability across a number of domains, including physical, psychological, social and occupational domains.

A recent systematic review by Graham, Rose, Grunfeld, Kyle and Weinman (2011) demonstrated that, compared to healthy controls, those with muscle disease had lower QoL in all areas of functioning. Evidence of decreased QoL is evident across a number of studies, with different NMD population groups and different measures of QoL. Individuals with NMDs have generally scored significantly lower than healthy controls on SF-36 subscales relating to role limitations, due to emotional problems and general mental health (Antonini et al., 2006; Kalkman et al., 2005). Using the same measure, other researchers have found that, among people with a range of NMDs, all aspects of QoL (both physical and psychosocial) were impaired, compared to the general population (Padua et al., 2009; Redmond, Burns & Ouvrier, 2008; Winter et al., 2010).

Similarly, using another multi-dimensional measure of health-related QoL (the TNO-AZL Adult Quality of Life questionnaire), individuals with various types of MD have been found to score higher on the depressive moods subscale and score lower on the vitality scale, when compared with healthy controls (Grootenhuis et al., 2007). Assessments of QoL using the Sickness Impact Profile have also demonstrated a poorer QoL in patients with NMDs (Piccinni et al., 2004).

In terms of the contributing factors to impaired QoL, the review by Graham et al. (2011) found strong evidence to show that illness severity, pain and mood significantly affected quality of life. The relationship between increased age and decreased QoL in NMDs has also been demonstrated by Piccinni et al. (2004). Similarly, Grootenhuis et al. (2007) found that emotional problems and general mental health worsened in relation to increases in participants' age, disease duration and disease severity, suggesting an increasing illness burden over time. These results are echoed in a number of studies where disease duration (Nätterlund, Sjöden & Ahlström, 2001; Sansone et al., 2010) and disease severity (Leonardi et al., 2010; Nätterlund & Ahlström, 2001; Redmond et al., 2008) were inversely related to QoL. Increased pain in NMDs has also been associated with lower general health perceptions, vitality, and social and physical role functioning; higher levels of fatigue and sleep disturbances; and less ability to cope with stress (Abresch et al., 2002).

There is, however, some conflicting evidence, in terms of the deterioration of an NMD being associated with poor QoL outcomes. For example, Padua et al. (2001) found no association between muscle deficit progression and decreased QoL in participants with myasthenia gravis (MG). Similarly, despite the fact that physical functioning is very restricted in conditions such as DMD, psychological components of QoL have been rated quite highly among those affected by this condition (Bach, Campagnolo & Hoeman, 1991; Kohler et al., 2005; Rahbek et al., 2005).

While the majority of existing studies have utilised specific QoL tools, some researchers have used clinical measures of depression to examine psychological well-being among those affected by NMDs. Winblad, Jensen, Månsson, Samuelsson and Lindberg (2010) found a higher prevalence of depressive symptoms among people with NMDs, compared to the general population, using the Beck Depression Inventory. Similarly, Duveneck, Portwood, Wicks and Lieberman (1986) found that those affected by DM were at greater risk of depression (as measured by the Minnesota Multiphasic Personality Inventory and the IPAT Depression test) than those in the general public or those in a non-progressively disabled control group.

In summary, there is a wealth of evidence, from studies using a variety of psychological measures, to show that living with an NMD can be associated with poorer well-being, especially in terms of reduced quality of life. While there is evidence to suggest that psychological well-being can be negatively impacted by illness progression, illness duration and age, this link is not consistent across all studies.

2.6.3 Social isolation in NMDs

A significant psychosocial implication of living with an NMD that has emerged from the QoL literature is disrupted social participation (e.g., Boström et al., 2005; Grootenhuis et al., 2007). Of the several domains of quality of life (including activities, independence, relationships, emotions and body image) examined in an Italian sample of adults with NMDs, it was found that activities and independence had a greater influence on quality of life than any other QoL domains (Sansone et al., 2010).

Disrupted social participation has been noted by people living with an NMD in areas such as mobility, housing, recreation and employment (Boström & Ahlström, 2004; Gagnon et al., 2008; Gibson, Young, Upshur & McKeever, 2007; Sadjadi et al., 2011; Vuillerot et al., 2010). Individuals with MD have reported that their condition impacts on their ability to be independent and spontaneous in the activities they undertake (Boström & Ahlström, 2004).

For people with MD, the negative impact of their condition on developing and maintaining social contacts has been found to be related to declining energy over time (Boström & Ahlström, 2004). Similarly, in DM, poor social participation has been associated with more severe muscle weakness and higher fatigue (Gagnon et al., 2008). For individuals with DMD, social interaction with peers can decline with age (Hendriksen et al., 2009), which may be due to the progressive nature of the condition.

Declining levels of social interaction have led to reports of social isolation and loneliness by individuals with NMDs (Ahlström & Sjöden, 1996), and of a negative impact on interpersonal relationships (Boström et al., 2005). Those affected by NMDs can experience a sense of grief related to lost independence (Arnold et al., 2005). Problems in starting and maintaining relationships have also been reported by some individuals affected by NMDs. This can be due to their illness and problems relating to a lack of

confidence in social and sexual situations, owing to a decreased satisfaction with their body image (Sadjadi et al., 2011)

2.7 Care-giving in NMDs

Neuromuscular disorders not only impact on the individual concerned, but also on their family members and care-givers. Many children and adults with NMDs need assistance with daily living and this support is often received at home from parents or other family members (Parker et al., 2005). Although many family members report a strong desire to support and protect the diagnosed individual (Boström, Ahlström & Sunvisson, 2006) and find strength and a sense of self-worth from caring (Samson et al., 2009), the role can pose a number of challenges to the carer's well-being. The following section will outline the practical challenges that are encountered when caring for someone with an NMD, the psychological impact and social isolation experienced by carers, and the coping mechanisms employed by care-givers.

2.7.1 Practical challenges in NMD caring

Care-giving in NMDs has been described as a chronically stressful experience (Buchanan, LaBarbera, Roelofs & Olson, 1979; Witte, 1985). Carers may be involved in a variety of care-giving tasks and have a range of responsibilities, from lifting and transferring their family member to assisting with feeding and personal care (Firth et al., 1983; Mah, Thannhauser, McNeil & Dewey, 2008). Carers may also find the difficulties of managing assistive technologies, such as breathing aids, stressful (Carnevale, Alexander, Davis, Rennick & Troini, 2006; Mah et al., 2008). Parents may worry about equipment and treatments for their children and often find caring exhausting (Plumridge, Metcalfe, Coad & Gill, 2010).

As well as managing day-to-day caring tasks, parents have to make difficult decisions regarding treatments, such as steroid treatments, and invasive surgical procedures, such as spinal fusion and tendon release (Nereo, Fee & Hinton, 2003). The financial impact of caring has also been identified as a stressor (Bothwell et al., 2002; Mah et al., 2008). Carers

have also reported a need to fight for their child's resource, information and support service needs (Firth et al., 1983; Plumridge et al., 2010).

In addition to the issues highlighted above, some parents of children with particular conditions, such as DMD, report difficulties in terms of dealing with their child's behavioural or emotional problems (Firth et al., 1983). Increased family stress has also been related to poorer intellectual functioning in boys with DMD (Reid & Renwick, 2001).

2.7.2 Psychological impact of NMD care-giving

Recurrent themes reported in qualitative studies of care-giving in NMDs highlight the emotional reactions carers may have to a family member's illness. These emotions include isolation, loss, sadness, guilt, confusion and anger (Boström et al., 2006; Bothwell et al., 2002; Carnevale et al., 2006; Firth et al., 1983; Gravelle, 1997; Mah et al., 2008; Nereo et al., 2003; Samson et al., 2009; Witte, 1985). Difficulties or delays in getting a diagnosis for their child added to the burden for some parents of children with NMDs (Firth et al., 1983; Webb, 2005; Plumridge et al., 2010).

Carers have discussed worries about their relative's disease progression and the uncertainty of their future (Boström et al., 2006; Buchanan et al., 1979; Gravelle, 1997; Mah et al., 2008; Samson et al., 2009). For parents of children with progressive conditions, this uncertainty was heightened every time there was a decline in their child's health due to their condition (Mah et al., 2008). Parents have been reported to dread the need for new adaptive devices, such as a powered wheelchair, as this signals further deterioration in their child's condition (Nereo et al., 2003; Mah et al., 2008).

Carers' sense of loss has not only been related to their family member's health deterioration, however, as personal loss is also experienced in relation to affected career aspirations and personal interests (Mah et al., 2008). Looking after a family member with an NMD has also been reported by carers to impact on family life in a number of ways. Some parents and couples experience a strain on marital relationships, due to low energy and lack of time for intimacy (Buchanan et al., 1979; Mah et al., 2008). Parents have also expressed concerns about the well-being of non-affected siblings who become involved in caring duties (Firth et al., 1983)

or who receive less attention due to their sibling's illness (Firth et al., 1983; Mah et al., 2008). Families also report difficulty in spending time together, alongside issues with going out as a family due to transportation constraints (Mah et al., 2008), e.g., if their child is a wheelchair user.

A number of concerns have also been noted by family members in relation to the genetic nature of these conditions. As mentioned previously, Boström and Ahlström's (2005) interview study revealed that family members and individuals affected by MD had multiple concerns related to the hereditary aspect of the disease. These included difficulties in: trying to come to an understanding of the condition; deciding whether or not to undertake genetic testing or whether to have children; and managing feelings of responsibility and guilt due to the inherited nature of the condition. Feelings of guilt related to inheritance are evident across a number of other studies of NMD carers (Buchanan et al., 1979; Gagliardi, 1991; Plumridge et al., 2010).

Parents have also reported difficulty in talking to their children about end-of-life issues, which can contribute to parental feelings of guilt (Witte, 1985). A fear of explaining the terminal nature of DMD to affected children has been reported in a plethora of qualitative studies (Boström et al., 2006; Buchanan et al., 1979; Abi Daoud, Dooley & Gordon, 2004; Firth et al., 1983; Fitzpatrick & Barry, 1986; Gagliardi, 1991; Plumridge et al., 2010; Witte, 1985). Family members' stress levels and QoL have also been found to be predictive of psychological adjustment and mental health among individuals with MD (Im, Lee, Moon, Park & Park, 2010; Reid & Renwick, 2001).

Studies that have used standardised measures of psychological well-being to examine the impact of caring for a child with an NMD indicate that care-giving is related to poorer psychological well-being. Nereo et al. (2003) found that mothers of children with an NMD had elevated stress levels when compared to a normative sample. The authors suggest that this may be due to the high number of problem behaviours these mothers are faced with. High levels of parental stress (Reid & Renwick, 2001) and lower psychological adjustment (Thompson, Zeman, Fanurik & Serotkin-Roses, 1992) have also been found among DMD carers. There is also evidence for elevated levels of depression and distress among parents of children with

DMD, when compared to a matched control group of parents (Abi Daoud et al., 2004). Caring in DMD has also been found to be associated with higher parental stress than caring for children with other chronic illnesses, specifically cystic fibrosis and renal disease (Holroyd & Guthrie, 1986). Disease severity has been found to contribute to higher parental stress (Holroyd & Guthrie, 1979).

While many NMD caregiver studies have focused on the experiences of DMD carers, few studies have quantitatively examined specific care-giver health in relation to a broader range of NMDs. An exception to this is a study of caregiver burden by Boyer, Drame, Norrone and Novella (2006). In a study of 56 dyads of individuals with different types of NMDs and their family carers, Boyer et al. attempted to quantify levels of carer burden and to investigate possible contributory factors. The authors found evidence of elevated carer burden among this diverse group of NMD carers. Factors which were found to impact on the risk of elevated burden included self-reported poor social functioning, carer anxiety and being a relatively younger carer (under 48 years of age).

2.7.3 Impact of NMD caring on social isolation

Social isolation has been identified as a main concern for DMD carers (Bothwell et al., 2002; Mah et al., 2008; Witte, 1985). Carers of people with NMDs have reported a decline in their social circles, due to the commitments involved in dealing with the condition (Gagliardi, 1991; Boström et al., 2006). Mothers are likely to give up work to be main carers when they have a child with DMD (Buchanan et al., 1979; Plumridge et al., 2010). Carers in employment have been found to have a significantly higher QoL than those not employed (Im et al., 2010), which may in part be explained by the increased level of social interaction enjoyed by those in work.

In terms of explaining the reasons for parents' social isolation, Mah et al. (2008) identified a number of factors. Parents struggled to co-ordinate trips out due to caring, faced a lack of understanding about their child's disease in social situations and found it difficult to maintain friendships due to a lack of opportunity to socialise. Isolation was also evident in parents' experiences with health care staff, where they often felt that care was not co-ordinated or managed in a way that met their children's needs

or their own needs. Difficulties in finding suitable home care also led to parents reporting difficulties in obtaining respite from their caring responsibilities.

2.8 Coping with NMDs

2.8.1 Practical measures in adjusting to NMDs

Practical measures that people with NMDs take to manage their condition include surgical interventions to help manage symptoms, such as spinal curvature operations, or the use of assistive devices, e.g., manual and powered wheelchairs, ventilation aids, etc. A number of benefits to using such devices have been documented. For example, the use of assisted ventilation has been associated with increased life expectancy in DMD (Eagle et al., 2002) and the use of a powered wheelchair has been found to increase young people's sense of independence and engagement in social activities, such as powered wheelchair football (Evans, Neophyte, de Souza & Frank, 2007; Gibson, Zitzelsberger & McKeever, 2009).

However, some people with NMDs have reservations about the use of assistive devices such as ventilation systems, as they feel the use of such machines is indicative of a progression in symptoms (Webb, 2005). Others feel that there is a stigma attached to the use of assistive devices, or that the physical burden of using such equipment is difficult (Brooks et al., 2004).

2.8.2 Coping with psychological aspects of NMDs

In terms of coping psychologically with NMDs, there is some evidence of how different coping styles are used by both individuals with NMDs and their carers. Coping has been described as a dynamic process involving an individual's cognitive and behavioural efforts to manage a specific stressful event or situation (Lazarus & Folkman, 1984). It has been proposed that there are two over-arching types of coping strategies: problem-focused and emotion-focused coping (Lazarus & Folkman, 1984; Lazarus, 1993). Problem-focused coping strategies involve active efforts to deal directly with a stressful situation. Conversely, emotion-focused coping strategies are described as approaches to managing emotions

arising from a stressful situation, without making attempts to change the situation itself. Others have conceptualised these main coping styles as approach or avoidant coping (Suls & Fletcher, 1985). In general, research suggests that problem-focused coping is linked to positive psychological and physical health outcomes when individuals are confronted by a stressful situation. However, emotion-focused coping may be useful for short-term or uncontrollable stressors (Taylor & Stanton, 2007).

Interview studies with people with NMDs suggest that individuals use a variety of coping responses, including both problem-focused and emotion-focused strategies (Ahlström & Sjödén, 1996; Boström & Ahlström, 2004). Emotion-focused responses (e.g., denial, avoidance) were reported twice as frequently, compared to problem-focused strategies, in Böstrom and Ahlström's study. The authors suggest that the tendency to use more emotion-focused coping could be due to the uncontrollable nature of most NMDs, which limits the utility of problem-solving approaches.

Specific approaches to coping used by people with NMDs include choosing to focus their energy on what is important to them (e.g., relationships) and/or taking a 'one day at a time' approach (Gibson et al., 2009; Nätterlund et al., 2001). Making downward comparisons, and noting that others are in more difficult situations, is another approach to coping with an NMD (Krause-Bachand & Koopman, 2008; Mah et al., 2008; Nätterlund et al., 2001). Interviews with people with SMA suggest that maintaining strong social relationships and trying to remain optimistic are key components of coping with their condition (Lamb & Peden, 2008).

There has been little research into the relationship between coping styles, coping resources and psychological well-being in NMDs. Initial research by Ahlström and Sjödén does suggest, however, that some coping mechanisms, such as stoic acceptance and trying alternative treatments, have been found to correlate with higher QoL outcomes. Conversely, mechanisms such as minimization, social comparison, establishing control over daily life, performing tasks with the aid of an appliance and accepting help were associated with lower QoL outcomes (Ahlström & Sjödén, 1996). Associations between certain coping styles and QoL were also explored by Nätterlund, Gunnarsson and Ahlström (2000). Specifically,

higher "hopelessness/helplessness" and higher "fighting spirit" scores were associated with poorer QoL scores.

Research studies focusing on coping in NMD caregivers is scant. Qualitative studies suggest that carers try to take a day-to-day approach, attempt to live life as normally as possible and try to focus on the positive aspects of caring. Parents of children with DMD have discussed the importance of taking a pro-active approach to learning about and adapting to their child's illness (Webb, 2005).

Mah et al. (2008) found that parents initially experienced stress when attempting to develop 'expert' knowledge on their child's needs. However, once they had become more informed regarding their child's condition, this mediated their stress, as they were better able to advocate for their child's needs with health care professionals. Parents also felt that knowing there were others who may be dealing with similar challenges helped them cope (Mah et al., 2008). Additionally, carers report comparing their lives to those who are less fortunate, in terms of the illness progression, as a way of accepting their current caring situation (Boström et al., 2006; Mah et al., 2008)

Outside support networks and groups offer a mechanism to improve coping for the parents of children with NMDs, as do fundraising and seeking information on research and treatment (Samson et al., 2009). Carers have often emphasised the importance of a strong support system (Lamb & Peden, 2008), reporting that support from family members can help to mediate their stress (Boström et al., 2006; Buchanan et al., 1979; Mah et al., 2008) and that support from understanding and accepting others has helped them to cope (Boström et al., 2006). The availability of knowledgeable and helpful care staff has also proved valuable to carers, helping them secure services and support in the community. Such services may include respite care which can help to reduce the care-giving burden on parents (Mah et al., 2008).

While the relationship between the NMD sufferer's coping styles and their carers' psychosocial health outcomes is not clear cut, supporting patients by helping them to develop coping resources may prove useful. Such coping resources may help individuals appraise stressful situations in a

more positive way, helping them develop a sense of control/mastery, self-esteem, optimism, and social support (Taylor & Stanton, 2007). Based on this, the remainder of this chapter will consider how social support interventions may be of benefit to those dealing with NMDs.

2.9 Supporting people with NMDs and their carers

The current literature suggests that living with an NMD and care-giving for those with NMDs can have negative psychosocial consequences. Of particular salience is the impact on feelings of social isolation. In the following section, the role of social support for people affected by NMDs is presented, along with an overview of existing psychosocial support interventions in this area. The chapter concludes with a brief outline of the potential benefits of online support groups (OSGs) for those affected by NMDs and their carers.

2.9.1 The potential role of enhanced social support in NMDs

Social support is defined as a "social networks' provision of psychological and material resources intended to benefit an individual's ability to cope with stress" (Cohen, 2004, p. 676). Cohen and Wills (1985) theorise that social support can serve to positively affect mental health (and/or physical health) directly via a main effect model or indirectly via a stress-buffering model. In the main effect model, an individual's level of perceived social support is a protective factor for health and well-being. In the stress-buffering model, perceived social support may moderate the negative impact of a stressful situation (e.g., by promoting coping responses) on psychological well-being.

Social support has been conceptualised in a number of ways, from the structure of one's available social network size (e.g., Sarason, Sarason, Potter & Antoni, 1985) to perceived satisfaction with functional aspects of support. This includes tangible, appraisal, self-esteem, belonging, emotional, affectionate, instrumental and informational support, along with positive social interaction (Cohen, Mermelstein, Kamarck, & Hoberman, 1985; Sherbourne & Stewart, 1991).

There is growing evidence that increased social support is related to better disease outcomes for patients and members of the general population (Frasure-Smith et al., 2000; Rutledge et al., 2004; Zhang, Norris, Gregg & Beckles, 2007; Tomaka, Thompson & Palacios, 2006; Uchino, 2006). More effective social support has also been linked to improved psychological health among patients (Kettman & Altmaier, 2008; Mazzoni & Cicognani, 2011) and care-givers (Klassen et al., 2007; Savage & Bailey, 2004). Additionally, higher levels of social support have been found to have a positive effect on how patients manage their illnesses and/or adhere to medical treatment (Di Matteo, 2004; Gallant, 2003).

In relation to NMDs, the existing literature suggests a potentially beneficial role for social support provision for those living with NMDs and their carers. For example, greater social support has been associated with better psychological functioning and less pain interference among those with DM and FSHMD (Miró et al., 2009). Higher social support has also been linked to lower psychological distress among mothers of children with a variety of chronic diseases, including MD (Dewey & Crawford, 2007), and better psychological adjustment in DMD carers (Thompson et al., 1992). In patients with MG, the availability of tangible support was a predictor of better mental health (Raggi, Leonardi, Mantegazza, Casale & Fioravanti, 2010). Additionally, increased family support has been related to higher levels of family resilience for those affected by NMDs (Chen & Clark, 2007).

2.9.2 Research on support intervention for NMDs
The extant literature on support interventions for NMDs is limited. Parents in a study by Bothwell et al. (2002) expressed a preference for the use of support groups over individual psychological or psychiatric services, in terms of helping their family deal with disease progression. However, studies on the use of support groups for NMDs are scant. One recent study by Hodges and Dibb (2010) examined parents' experiences of using a DMD support organisation, highlighting some of the benefits of peer support. By comparing their situation with others who seemed to be coping well with DMD, parents were able to have a more positive outlook. Parents could also learn from any mistakes others had made. When they compared their situation to those of families whose child's condition had

deteriorated further than their own, parents felt thankful for the level of ability that their child had, but this also led to worries about their child's disease progression.

Being part of a support group for DMD allowed parents to feel a sense of belonging by getting involved in the organisation and exchanging information (Hodges & Dibb, 2010). Parents reported a sense of empowerment related to becoming involved in fundraising events, for example. Parents of children whose condition was progressing also sought out support and advice in dealing with the practicalities of caring from other experienced parents. In return, giving advice to other parents helped to provide a sense of purpose and enjoyment.

Other support interventions in NMDs have included multi-component rehabilitation programmes for affected individuals (Ahlström, Lindvall, Wenneberg & Gunnarsson, 2006; Hartley, Goodwin & Goldbart, 2011; Nätterlund & Ahlström, 1999). One rehabilitation programme for individuals with MD, reported in two separate studies, included: group sessions addressing patients' medical care needs; administering treatments and prescribing assistive devices; providing education on the condition and available services; facilitating experience exchange between patients; and providing individual psychosocial support when needed (Ahlström et al., 2006; Nätterlund & Ahlström, 1999). While no significant changes were found in measures of activities of daily living, coping or psychological well-being (Ahlström et al., 2006), a number of benefits to participation were noted in a qualitative study examining patients' experiences (Nätterlund & Ahlström, 1999).

The benefits of participation in Nätterlund & Ahlström's (1999) study were multiple. Participants valued being able to ask questions about their condition to trustworthy staff and having the opportunity to meet others with the condition. The programme helped participants feel like they were part of a community; therefore, they felt less lonely in their experiences. Participants also felt that the sessions helped them and their relatives to identify alternative ways of coping with their difficulties relating to NMDs. The practical help in managing their condition and the medical advice, information, and treatments received were also highly valued.

Similarly, those with MD taking part in an exercise intervention also cited contact with other people with MD as one of the main benefits of participation (Wenneberg, Gunnarsson & Ahlström, 2004). This finding is consistent with the study conducted by Hartley et al. (2011), which evaluated participants' experiences of attending a specialist neuromuscular centre. Participants valued the opportunity to meet others socially, develop their knowledge from meeting others with the condition and learn from others about ways of coping. The availability of specialist knowledge was also highly valued.

In summary, the literature on psychosocial interventions for individuals affected by NMDs is relatively limited. A common thread to the studies cited above is the beneficial effects that people with NMDs and their carers report in relation to accessing increased social support. As living with NMDs has been associated with decreased social opportunities, which can worsen with the progression of the disease, and carers have reported feeling significantly isolated, it is appropriate to consider in more detail the role of social support in families' adjustment to NMDs.

As highlighted above, families have unique information support needs related to interpreting an NMD diagnosis, understanding genetic inheritance, and finding out about service provision and practical ways to manage living with the condition. As pointed out by Ahlström et al. (2006), there are difficulties with conducting interventions with people from rare disease groups, especially in terms of recruiting sufficient participants to take part in the intervention and in forming relevant control groups. Some of these difficulties would also apply to service provision. While supportive interventions in NMDs would be desirable, those with the condition and their carers may come from geographically diverse areas, which may render the organisation of face-to-face group support programmes difficult. For those affected by NMDs, travelling to such groups may also be a barrier to participation. Additionally, carers may also find it difficult to find time to attend such groups due to caring commitments.

Despite these barriers to support provision in NMDs, it is important to evaluate support interventions to work towards identifying the most appropriate forms of support for people affected by NMDs. It is clear from

the studies on support interventions in NMDs discussed above that people affected by NMDs and their carers may value the social opportunity to interact with others facing similar situations and share informational support, as well as advice, about coping with an NMD.

2.9.3 The potential role of online support groups in NMDs

The use of the Internet has provided a new medium for people to access support related to health issues. The majority of internet users have been found to use the internet for health-related information (Atkinson, Saperstein & Pleis, 2009). Health-related OSGs have also gained prominence as a source of support for people affected by a variety of health concerns and their carers. These virtual communities allow people to build social networks outside of traditional geographical boundaries (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004). Communication in such groups is often facilitated by e-mailing, discussion boards, and chat facilities.

Online support groups may be more accessible for people with NMDs and their carers, when compared with other services. Accessing an OSG may be easier for those with physical disabilities than traditional face-to-face groups (Braithwaite, Waldron & Finn, 1999; White & Dorman, 2001). OSGs may also be beneficial for carers, who may have difficulty accessing traditional face-to-face support groups due to their caring commitments. OSGs also have the potential to provide members with 24-hour access to support, and the lack of geographical boundaries allows members to access a wider, more diverse support network (Coulson, 2005; White & Dorman, 2001). This may be particularly important in NMDs, as conditions are rare, thus limiting support from others who also have experience of the same condition.

Previous research in the U.K., in which families of children with DMD were given a computer with internet access, indicated that there were positive effects of internet access on both family relationships and on the child's feelings of isolation (Soutter et al., 2004). There is preliminary evidence that families affected by NMDs have started to use OSGs in relation to the condition, and that parents value the contact with other families of children with NMDs as a peer support system (Mah et al., 2008). Little is known about the specific impact of parents' contact with other parents in

these groups. There is currently no available research on how people with an NMD or their carers use OSGs, and any associated outcomes of participation. The following chapter will present an overview of the current research on online support communities.

Chapter 3: Online Support

3.1 Introduction

This chapter will present current research on patients' and carers' use of online support groups (OSGs), the processes of support offered through these online communities and the current evidence on outcomes of OSG participation. An overview of different methodologies that have been used to research OSGs will also be provided. Through this review, gaps in current knowledge on OSG use will be identified.

3.2 The rise of online health-information seeking

The internet is used worldwide by 2.2 billion people, which represents a growth of 538% in the period from 2000 to 2011 (Miniwatts Marketing Group, 2012). There has been a simultaneous growth in the number of people seeking information and support about health-related issues online (Fox, 2008). Research conducted in the United States shows that 80% of internet users search for health-related information online (Fox, 2011). In the U.K., recent statistics suggest that 42% of internet users had accessed health-related information over a three-month period (ONS, 2011). Caregivers have been found to be prominent seekers of online health-related information, with 88% of internet-using caregivers in the U.S. seeking health information on the internet (Fox & Brenner, 2012).

The availability of online health information encourages people to become active and informed health-care consumers (Powell, Darvell & Gray, 2003). Wald, Dube and Anthony (2007) describe how the internet facilitates a consumerist model of health information exchange, whereby information is triangulated between the patient, internet information sources and the health care provider. The importance that internet users ascribe to the internet as a source of health information has also increased. In a survey conducted in seven European countries, the percentage of participants who perceived the internet to be an important source of health information rose from 6.5% to 46.8% from 2005 to 2007 (Kummervold et al., 2008). In terms of the impact of health information

seeking, Fox and Rainie (2002) found that 61% of internet health information seekers felt the internet had improved the way they look after their health.

Patients are using medical information found online in various ways before, during and after medical consultations. Almost three-quarters (74%) of primary health care providers surveyed by Malone et al. (2004) had encountered patients who had brought information that they retrieved from the internet into a consultation. Similarly, the majority of online health information seekers have been found to discuss online health information with their doctors (AlGhamdi & Moussa, 2012; Fox, 2008) and to seek information online after medical appointments (Bell, Hu, Orrange & Kravitz, 2011).

Online health information seekers use information to ascertain the need for a medical appointment (Attfield, Adams & Blandord, 2006), satisfy curiosity about health issues (AlGhamdi & Moussa, 2012; Bell et al., 2011), help diagnose problems and feel more comfortable about advice given by health professionals (Ybarra & Suman, 2006). Patients also seek health information to redress a perceived lack of information from doctors (AlGhamdi & Moussa, 2012; Kivits, 2006), to prepare for medical appointments or help influence the outcome of medical encounters (Attfield et al., 2006; Hu, Bell, Kravitz & Orrange, 2012; Kivits, 2006) and to verify diagnosis or treatment suggestions post-consultation (Attfield et al., 2006). Elevated anxiety levels or a change in anxiety levels post-medical appointment has also been related to seeking health information online (Bell et al., 2011).

Apart from seeking factual medical information, internet users have also been found to seek out the experiences of others who have similar health concerns. For example, 34% of internet users in the U.S. have read about someone's illness commentary or experience on newsgroups, websites or blogs (Fox, 2011). Eighteen percent of internet users have used the internet to find others with similar health concerns, while 5% have posted health comments, questions or information about health or medical issues in an OSG (Fox, 2011).

One obvious short-coming of internet-based support for health issues is the fact that not all patients and family members are able to access the internet, a phenomenon known as the 'digital divide' (e.g., Brandzaeg, Heim & Karahasanović, 2011). The highest levels of internet penetration are currently in North America, Oceania and Europe (Miniwatts Marketing Group, 2012). Specific demographic factors can impact individuals' access to the internet. For example, people who were better educated, more affluent, from urban areas, white, younger and those without disabilities were found to be more likely to use the internet in the U.S. (Pew Research Institute, 2005). There is also an acknowledged digital divide in terms of carers' ability to access the internet. Factors such as age, housing tenure, employment status and number of hours involved in caring have been found to influence internet use among carers (Blackburn & Read, 2005; Blackburn, Read & Hughes, 2005).

Discrepancies can also be seen in terms of who accesses health information online. For example, women (AlGhamdi & Moussa, 2012; Atkinson et al., 2009; Cohen & Adams, 2011; Kummervold et al., 2008; Pew Research Institute, 2005,), young adults aged 25 to 44 (Cohen & Adams, 2011), those with higher education levels (AlGhamdi & Moussa, 2012; Atkinson et al., 2009; Cohen & Adams, 2011), and those who are employed (AlGhamdi & Moussa, 2012) or have higher income levels (AlGhamdi & Moussa, 2012; Cohen & Adams, 2011), are more likely to seek health information online. Improved internet access and faster connection speeds (Atkinson et al., 2009), and higher internet skills or e-health literacy (Hu et al., 2012; Ybarra & Suman, 2006) have also been related to higher use of the internet for health-related information. Individuals suffering from a chronic disease, or those with health concerns or poorer self-rated health, have been found to be more likely to seek health information online (Fox & Purcell, 2010; Hu et al., 2012; Ybarra & Suman, 2006).

There is, however, evidence that this digital divide is closing. Internet access has steadily grown in the U.K. from 70% in 2009 to 73% in 2010, 77% in 2011 and 80% in 2012 (Office for National Statistics [ONS], 2009, 2010, 2011, 2012). The use of the internet for health-related information is also becoming more popular in the U.K., with the number of people reporting using the internet for health-related information increasing

from 34% in 2009, to 39% in 2010 and 42% in 2011 (ONS, 2009, 2010, 2011). It is likely that, as internet access is growing, this digital divide is becoming less pronounced.

3.3 Online support groups – an introduction

There is a wide variety of sources of health information and support available online, from information-based websites, to e-therapy groups, to online support groups. OSGs retain many of the features of traditional face-to-face self-help peer support groups, but these groups are created and supported using electronic media (Braithwaite et al., 1999; Finn, 1999; Salem, Bogart & Reid, 1997). OSGs have been described as:

> "…a group of individuals with similar or common health related interests and predominantly non-professional backgrounds (patients, healthy consumers, informal caregivers) who interact and communicate publicly through a computer communication network such as the internet, or through any computer based tool…allowing social networks to build over a distance"
>
> (Eysenbach et al., 2004, p.1).

OSGs have also been identified as a low-cost type of supportive intervention for those affected by health issues (Winzelberg, 1997).

There are numerous types of OSGs. Groups are differentiated by a number of characteristics such as privacy level, the types of support offered, user characteristics, the level of moderation, the characteristics of the moderators (e.g., patients, carers, professionals, etc.) and the modality by which support is delivered. OSGs were initially developed using e-mail lists and message boards, which were either synchronous or asynchronous. Recent technologies have allowed OSGs to form around illness blogs and social networking sites (Bender, O'Grady & Jadad, 2008). Groups can be moderated or non-moderated for content. They can also be facilitated or led by health professionals or lay people who may direct the content of the conversations. This review will focus on peer-run OSGs, which may be moderated but are not professionally-led in terms of content.

3.4 Unique features of OSGs

There are a number of features of online support groups which make this a unique social support medium. The following sub-sections will present a number of these features of online support. Theoretical and empirical observations will be noted relating to the potential advantages and disadvantages of OSGs.

3.4.1 Access to a large, diverse support network of similar others

As there are generally no limits to the number of people taking part in OSGs, these groups can offer access to a large, potentially international network of supportive others (White & Dorman, 2001; Wright & Bell, 2003). Wright and Bell describe the connections people make on OSGs as 'weak ties'. They suggest that the benefit of these weak ties is the heterogeneity of people available and the objectivity of the advice and support these people can offer. This large network allows members to connect with others with highly diverse viewpoints (Wright & Bell, 2003) and who may be from different demographic backgrounds (Coulson, 2005; Coulson, Buchanan & Aubeeluck, 2007). The variety of members in OSGs has been found to be useful for participants, in terms of gathering a broader and more diverse range of ideas and opinions about coping with health issues (Coulson & Knibb, 2007).

While participants value the diversity of member experiences within online groups, similarities between experiences are also valued (Wright, 2000; Im et al., 2007). By meeting others who share similar health experiences, OSG participants feel they are likely to receive support or information from people who may understand their situation better than face-to-face acquaintances (Walther & Boyd, 2002). Perceptions of similarities between OSG members and identification with common experiences have been found to be important benefits of participation (Wright, 2002). Wright (2000) found that perceived similarity between OSG members was related to the size of members' online network and their satisfaction with their online network.

There are a number of ways in which meeting a large group of similar people may be helpful for OSG users. Older adults using OSGs felt that meeting similar others helped to create understanding and empathy and

allowed members to offer more helpful advice, due to their personal experience (Pfeil, Zaphiris & Wilson, 2009). Seeking out like-minded people on OSGs helps members to reinforce or validate personal opinions and experiences (Sillence, 2010), authenticating members' illness experiences (Barker, 2008). Building this network of access to people with similar problems may be particularly important for those with mobility difficulties, as OSGs have been found to enhance members' abilities to build their social network (Tanis, 2008). Similarly, for those dealing with uncommon diseases, OSGs may provide one of the only mechanisms for people to connect with others who also have their disease (White & Dorman, 2001; Davison, Pennebaker & Dickerson, 2000).

It must be noted, however, that there are potential disadvantages of accessing such a large network of people who will all have slightly different illness experiences. Members of OSGs can sometimes find it distressing to read about other members' illness progression (Han & Belcher, 2001; van Uden-Kraan, Drossaert, Taal, Lebrun et al., 2008). Reading other members' stories may lead OSG users to realise the full implications of their own illness (Høybye, Johansen & Tjørnhøj-Thomsen, 2005). Similarly, studies of those who have left breast cancer OSGs suggest that these people wanted to protect themselves from the negative aspects of the disease, such as meeting those whose cancer had metastasised (Sandaunet, 2008; Vilhauer, McKlintock & Matthews, 2010). As well as feeling upset or troubled by negative aspects of the experiences of others, there is some evidence that members can also feel distressed by positive health news reported by others. For example, Malik and Coulson (2008) found that some OSG members found it difficult to read both stories of unsuccessful infertility treatment and accounts of fertility success stories.

A final potential disadvantage of having access to a large network of others with similar experiences is that disagreements may also emerge due to the diversity of members and their opinions (Attard & Coulson, 2012). The large number of members can also lead to problems dealing with the volume of information posted and the large amount of potential 'noise' or off-topic conversations (Han & Belcher, 2001).

3.4.2 Anonymity and lack of physical cues

Another unique aspect of OSG communication is the increased anonymity this medium can afford for disclosing sensitive information, in comparison to face-to-face support opportunities (e.g., Klemm & Nolan, 1998; McKenna & Bargh, 1998). Apart from anonymity, a lack of physical contact has been found to facilitate disclosure about difficult or painful subjects in participants on a breast cancer forum (Høybye et al., 2005). Similarly, some participants value being protected from the reality of seeing others physically affected by their illness (Vilhauer et al., 2010).

In describing the online disinhibition effect, Suler (2004) suggests that factors such as anonymity, invisibility, asynchronous online communication and the minimisation of power differentials through the lack of physical cues, may bolster an individual's capacity to disclose online. The anonymity inherent in OSGs may mean that interacting in OSGs involves less personal and social risk than face-to-face interactions (Caplan, 2003), and so OSGs may facilitate higher self-disclosure than face-to-face groups (Salem et al., 1997; Joinson, 2001; Tidwell & Walther, 2002).

Some OSG users feel that they can disclose sensitive information, which they would otherwise be unable to discuss outside of the online community setting (Powell, McCarthy & Eysenbach, 2003; Broom, 2005a, 2005b). Several researchers have noted the potential benefits of anonymous interactions on OSGs for those with stigmatising conditions (e.g., Braithwaite et al., 1999; McKenna & Bargh, 1998; White & Dorman, 2001; Wright, 1999, 2000, 2002; Wright & Bell, 2003). This anonymity has been endorsed as an important aspect of online support by those affected by such conditions (e.g., Buchanan & Coulson, 2007; Tanis, 2008; Walther & Boyd, 2002; Wright, 2000).

Analyses of online group discussions have shown that participants disclose information about a range of intimate or sensitive issues (Attard & Coulson, 2012; Gooden & Winefield, 2007; Malik & Coulson, 2008; Sullivan, 2003; Springer, Reck, Huber & Horcher, 2011). OSG communication has been found to be an acceptable and sometimes preferential format for the discussion of sensitive health issues. For example, for those discussing sexual issues related to gynaecological

cancer, participants valued the protection of their identity provided by the online format (Wiljer et al., 2011). Similarly, Classen et al. (2012) found that the majority (79%) of participants in a professionally moderated online discussion group for gynaecological cancer felt they were more comfortable discussing sexual concerns in the online group than they would be in a face-to-face group. Seventy-nine percent of participants in an OSG for people with body image concerns also reported that online chats were better than face-to-face conversations (Zabinski, Celio, Jacobs, Manwaring & Wilfley, 2003).

The lack of physical contact or closeness to others, however, has been noted as a disadvantage of online support by some members (Han & Belcher, 2001). This feature of OSGs can create concerns for users, in terms of retaining anonymity, privacy and safeguarding personal information (Im et al., 2007).

3.4.3 Potential for misunderstandings and uninhibited behaviour
Commentators have noted the potential for 'flaming' or verbal harassment as a potential disadvantage of OSGs, which may be exacerbated by the inherent anonymity the medium affords (White & Dorman, 2001; Wright, 2000; Wright & Bell, 2003). Early discussions of online communication, including social presence theory (Short, Williams & Christie, 1976) and the lack of social context cues hypothesis (Sproull & Kiesler, 1986), suggested that a lack of social norms and the absence of normal interactional cues could lead to less inhibited and potentially negative or hostile online communication.

Some people have reservations about using online support due to concerns about such misunderstandings or misbehaviour (Pfeil et al., 2009). Flaming has been described by O'Sullivan and Flanagin (2003) as an act which is intended to violate the interactional norms of a group. Dealing with misbehaviour such as persistent spamming and/or dealing with those who re-join an OSG with multiple identities have been identified as drawbacks of OSGs, especially for OSG moderators (Hsuing, 2000).

Feedback from OSG users suggests that members do, on occasion, feel attacked by comments posted by others, but this experience seems to be

infrequent (Greer, 2000; Klaw, Huebsch & Humpheys, 2000). A number of researchers have analysed the content of messages for the existence of negative or damaging statements and have found that less than 1% of messages contain this type of content (Finn, 1999; Malik & Coulson, 2011; van Uden-Kraan, Drossaert, Taal, Lebrun et al., 2008).

Some research does suggest that a lack of visual or verbal cues can make it more difficult to understand or correctly interpret the tone of messages in OSGs (Attard & Coulson, 2012; Han & Belcher, 2001; Høybye et al., 2005; Pfeil et al., 2009). Misunderstandings which lead to disagreement or negative feelings can be a disadvantage of OSG communication participation (Malik & Coulson, 2008). OSG members have also adopted strategies for compensating for misunderstandings. Such strategies include clarifying meanings (Attard & Coulson, 2012) and using non-verbal cues (e.g., emoticons and adapted punctuation) to convey or modify meaning, with some groups even creating language specific to the group itself (Braithwaite et al., 1999; Malik & Coulson, 2008; van Uden-Kraan, Drossaert, Taal, Lebrun et al., 2008).

3.4.4 The potential for misinformation

Credibility of information in online groups has been found to be an important factor in members' satisfaction with participation (Wright, 2000). The absence of physical cues and anonymity inherent in OSGs has, however, given rise to concerns about the quality of medical information available online generally (Eysenbach & Diepgen, 2001) and in OSGs specifically (Winzelberg, 1997; Coulson & Knibb, 2007; Pfeil et al., 2009). Some people do not use OSGs due to fears of misinformation or deception (Broom, 2005a). Groups such as pro-anorexia OSGs or other negative-enabling groups are known to be providers of medically controversial information (e.g., Gavin, Rodham & Poyer, 2008; Haas, Irr, Jennings & Wagner, 2010).

Early studies have suggested that there is a relatively high amount of medically inaccurate or unconventional posts to OSGs. For example, 36% of posts in a study by Culver, Gerr and Frumkin (1997) and 12% of posts that were analysed in a study by Winzelberg (1997) were considered inaccurate or unconventional. However, more recent studies have contradicted these findings. Content analyses of OSG postings have

revealed that the majority of messages are not erroneous or harmful, with misinformation or harmful information being reported in different OSGs in 0% to 8.6% of posts (Esquivel, Meric-Bernstam & Bernstam, 2006; Hwang et al., 2007; Hoch, Norris, Lester & Marcus, 1999; van Uden-Kraan, Drossaert, Taal, Lebrun et al., 2008).

Despite concerns about the potential impact of any misleading information in OSGs, it would appear that OSGs often have a self-correcting nature, whereby any misleading information is amended by members over time (Esquivel et al., 2006; Hwang et al., 2007). Participants have also been found to warn each other against trying unproven therapies (Feenberg, Licht, Kane, Moran & Smith, 1996) and to advise each other about the need for sound medical advice and not to rely solely on group information (Attard & Coulson, 2012).

3.4.5 Lack of physical and temporal barriers to participation

OSG members can access support from the comfort of their own home at any time, allowing people with limited mobility to take part (Braithwaite et al., 1999; Davison et al., 2000; Finn, 1999; White & Dorman, 2001; Wright, 2002; Wright & Bell, 2003; Vilhauer, 2009). The lack of need to travel to access support has been identified as advantageous by cancer patients using OSGs (Im et al., 2007; Vilhauer, 2009). The ability to seek information or support at any time is a helpful feature of OSGs for participants (e.g., Coulson & Knibb, 2007; Han & Belcher, 2001; Im et al., 2007; Malik & Coulson, 2008; Pfeil et al., 2009; Vilhauer, 2009; Walther & Boyd, 2002), who have been found to access such support sites at all hours of the day and night (e.g., Brennan, Moore & Smyth, 1995; Gustafson et al., 1994; Winzelberg, 1997). As there is no imposed limit on the time spent accessing online support, there is some evidence that OSG group members may interact more frequently than members of comparable face-to-face support groups (Alemi et al., 1996; Campbell et al., 2001).

3.4.6 The ability to choose activity level in OSGs

A unique aspect of participation in OSGs is the ability of participants to choose whether they would like to reveal themselves in the group or whether they choose to just read other people's communication (King & Moreggi, 1998; Winzelberg, 1997), a phenomenon known as 'lurking' (Preece, Nonnecke & Andrews, 2004). Lurking can be valuable for those

who want to learn from others' experiences but do not want to ask questions (Broom, 2005a). Lurkers have been found to constitute approximately half or more of the participants in OSGs (Nonnecke & Preece, 2001; Freeman, Barker & Pistrang, 2008).

Lurkers' reasons for not actively taking part are numerous and include feeling that they don't need to post, that they are still learning about the group (Preece et al., 2004; Nonnecke, Andrews & Preece, 2006), or feeling shy about posting (Nonnecke et al., 2006; Nonnecke & Preece, 2001). Feeling it was more helpful not to post, having software problems, and not liking group dynamics have also been cited as reasons for lurking (Preece et al., 2004). Further reasons noted by lurkers include concerns about anonymity, coping with the volume of messages posted to the group, having limited time (Nonnecke & Preece, 2001) and not feeling as though their health condition was sufficiently serious to merit posting (Sandaunet, 2008).

Members who post most often or are at later stages of the membership cycle can be contrasted with lurkers. Nimrod (2012) suggests that the membership cycle begins with an individual feeling distressed, which leads to the person taking part and becoming either an active help receiver or a passive follower (lurker). Some users will then become active help providers, or 'OSG veterans', who may feel more able to help others than members at earlier stages of the membership cycle. Describing these more established members as 'leaders' or 'elders', Kim (2000) describes how these frequent posters often share information and explain the culture of the website.

3.4.7 Asynchronous communication

Online support communication is often based on asynchronous communication formats, which allow members to carefully consider the information provided before posting a response. Theoretically, asynchronous communication may help in facilitating personal communication (Walther, 1996). Increased message-editing abilities in online asynchronous communication may allow members to be more selective in their self-presentation and to engage in more intimate interactions (Tidwell & Walther, 2002; Walther, 1996). OSG members have been found to value the opportunity that asynchronous

communication affords members to reflect on their thoughts before posting (Malik & Coulson, 2008; Vilhauer, 2009; Shaw, McTavish, Hawkins, Gustafson & Pingree, 2000; Pfeil et al., 2009).

A potential disadvantage of asynchronous communication is that there may be less certainty about whether or not a participant will receive a response to a post, or when they will receive a reply (Wright, 2000). A lack of replies or low activity levels have been noted as disadvantages in some OSGs (Attard & Coulson, 2012; Coulson & Greenwood, 2012), especially in times of immediate need (Pfeil et al., 2009). While there have been concerns about the immediacy of support available, van Uden-Kraan, Drossaert, Taal, Lebrun et al. (2008) found that messages to a variety of OSGs were generally answered within 24 hours of being originally posted.

3.5 Reasons for OSG use

3.5.1 Who uses OSGs?

Health-related variables such as self-reported poor or fair health and lower income have been related to the use of OSGs for health issues (Atkinson et al., 2009). Internet users affected by chronic disease are also more likely to contribute to OSGs (Fox & Purcell, 2010). It has been reported that 37% of internet users living with a chronic disease may read about others' health experiences on blogs, listservs, discussions or online groups that help with personal and health issues, while 7% of internet users with chronic disease may actively contribute to such services (Fox & Purcell, 2010).

The use of OSGs has been associated with curious patients and more autonomous patients (Santana et al., 2011). Members often tend to be affected by the condition that the OSG represents. For example, Powell, McCarthy and Eysenbach (2003) looked at the characteristics of internet depression support group users and found that 40% to 64% of members had major depression.

Some researchers have examined the profile of OSG users in comparison to face-to-face support group users. Lieberman (2007a) found that those using a Parkinson's disease online forum were younger, less depressed

and had higher QoL scores than members of comparable face-to-face support groups. However, Klemm and Hardie (2002) found that depression scores were higher in OSG users than in face-to-face cancer support group users. The extent to which online support users represent those who traditionally may seek face-to-face support is still not clear.

Greater use of OSGs has been found in individuals with certain chronic health problems, such as depression, anxiety, stroke, diabetes, cancer and arthritis (Owen et al., 2010). Worse health status (Chou, Hunt, Beckjord, Moser & Hesse, 2009; Owen et al., 2010), higher psychological distress (Chou et al., 2009) and being affected by a stigmatised illness such as HIV (e.g., Davison et al., 2000) have also been associated with with OSG use.

Higher use of OSGs has also been found among those with certain demographic and personal factors such as higher education, higher income (Owen et al., 2010; Han & Belcher, 2001) and higher confidence in receiving support online (Eastin & LaRose, 2005). Gender differences are also apparent in OSG participation, with females tending to use mixed gender OSGs more (Bragadòttir, 2008; Hu et al., 2012; Klaw et al., 2000; Mo, Malik & Coulson, 2009). Those not from ethnic minority groups have also been found to have a higher use of OSGs (Gustafson et al., 2001; McTavish, Pingree, Hawkings & Gustafson, 2003; Han & Belcher, 2001; Hesse et al., 2005; Hu et al., 2012; Im, Lee & Chee, 2011; Mo et al., 2009).

A number of studies have explored differences between male and female participants' communication patterns in OSGs. Studies which have compared communication in OSGs relating to female or male cancers suggest, with some some exceptions (e.g., Gooden & Winefield, 2007), that communication in women's cancer OSGs is more emotion-focused, while there is a greater emphasis on informational support in male cancer OSGs (Blank & Adams-Blodnieks, 2007; Blank, Schmidt, Vangsness, Monteiro & Santagata, 2010; Seale, Ziebland & Charteris-Black, 2006; Sullivan, 2003).

However, several authors have failed to find gender differences in the content of communication patterns on mixed-gender boards (Klaw et al., 2000; Salem et al., 1997). In their systematic review of gender differences in OSG use, Mo et al. (2009) found that, in studies that compared male and female cancer discussion boards, there was some evidence of gender

differences. However, in mixed-gender boards, these differences were less evident. Gender differences could therefore be related to disease aspects of the studied groups rather than inherent gender differences.

3.5.2 Why use OSGs?

A number of factors that influence the decision to begin using OSGs have been identified. For example, Im (2011) synthesised factors relating to cancer OSG use into 5 over-arching factors: disease factors, background characteristics (including demographic factors and perceived social support), cultural factors, needs (e.g., psychological, informational, etc.) and internet use factors. One of the main reasons for OSG use is information seeking or advice seeking (Han et al., 2010; Bunde, Suls, Martin & Barnett, 2006), with OSG use more likely for those with unmet information needs (Bender et al., 2012). This purpose of OSG use is reflected in the high number of posts to OSGs that ask questions of other members. For example, Hoch et al. (1999) found that 80% of initial posts to an epilepsy forum were questions related to treatment options and the natural history of the illness. Similarly, Greer (2000) found that members generally created their first post to a cerebral palsy mailing list when they had a pressing problem.

As well as requesting information support, people using OSGs also seek emotional support and interaction with similar others (e.g., Im et al., 2007; Lieberman & Russo, 2001). When surveyed, the majority of parents who had joined a Rett syndrome listserv primarily did so to gain information about their child's condition (Leonard et al., 2004), but approximately half of these parents joined the group in order to share their experience or to seek emotional support. Similarly, minimising the isolation that can result from an illness has been found to be a key motivator for joining a breast cancer forum (Høybye et al., 2005).

Turner, Grube and Meyers (2001) proposed an optimal match theory as to why people seek support on OSGs. The authors found that people participated more in online cancer communities when support available in the group was high and support available from a significant other person in their lives was low. Han et al. (2012) found that those living alone and those who need more health information were more likely to post rather than lurk on a breast cancer OSG. The authors suggest that this supports a

social compensation model of OSG use, where members may use online social support in response to a lack of psychosocial resources. Similarly, in individuals with hearing loss, there was a correlation between OSG activity and lower levels of support from family or friends (Cummings, Sproull & Kiesler, 2002). However, in another study of OSG users, perceived social support levels were unrelated to online support activity (Eastin & LaRose, 2005), which suggests that OSG use may not always be due to a lack of support in the participant's offline environment.

Davison et al. (2000) suggest using Festinger's (1954) theory of social comparisons in order to understand why people seek online support. The authors suggest that people may use online support because, in times of uncertainty, people's interactive behaviour can increase as they seek out the opinions of others, in terms of how they should be thinking or feeling. Indeed, participants in Bunde et al.'s (2006) study of an OSG for hysterectomy patients placed greater value on the support from those who had similar demographic profiles (in terms of religion, ethnicity, parental and operative status). This supports the suggestion that support from similar others is highly valued.

People may also participate in OSGs if they have an intrinsic interest in health issues (e.g., Dutta & Feng, 2007). Perceived susceptibility to being diagnosed with a disease may also trigger participation in disease-specific OSGs (Dutta & Feng, 2007). Having concerns related to a health issue or requiring help with a specific health issue has also been shown to be a motivating factor for using online support (Buchanan & Coulson, 2007; Tanis, 2008). Others may use OSGs to help gain a sense of control over their illness experience (Broom, 2005b).

3.6 Communication patterns in OSGs

The analysis of communication within OSGs provides important information as to the type of messages participants exchange and how groups function. It also allows for the examination of any underlying therapeutic or social support processes. The following sub-sections will describe three main types of analyses of OSG communication. The first sub-section relates to research that has examined the social support functions of OSG communication. The second sub-section describes

research regarding the presence of therapeutic or self-help processes in OSG communication. Finally, an overview of analyses of the content of OSG communications, without a pre-defined theoretical framework, will be presented, in order to illustrate the utility of inductive approaches in examining the concerns of OSG members and any unique processes in OSG communication.

3.6.1 Social support exchange

A number of researchers have content-analysed postings to OSGs using theoretical frameworks of social support. Braithwaite et al. (1999) were amongst the first researchers to undertake such a study when they examined the types and the frequency of expression of social support in an internet discussion group for people with disabilities. Using a modified version of Cutrona and Suhr's (1992) system of categorising social support, the authors found that emotional and informational support were key features of the online conversations, followed by esteem support, with less evidence of tangible assistance and network support.

Using the same theoretical framework to guide content analyses, a number of authors have confirmed the existence of all five types of support in OSG communication and have noted the prominence of information and emotional support. These results have been found in relation to Huntington's disease (Coulson et al., 2007), HIV/AIDS (Coursaris & Liu, 2009; Mo & Coulson, 2008) and childhood cancer forums (Coulson & Greenwood, 2012). Similarly, Coulson (2005) used a deductive thematic analysis of messages to an irritable bowel disease OSG and found evidence for the five main types of supportive behaviour identified by Cutrona and Suhr (1992).

Content analyses of postings to OSGs that have used alternative coding frameworks related to social support also reveal the primacy of information giving and receiving (White & Dorman, 2001; Evans, Donelle & Hume-Loveland, 2012; Klemm, Hurst, Dearholt & Trone, 1999) and emotional support or encouragement (Chuang & Yang, 2012; Evans et al., 2012; Klemm et al., 1999).

3.6.2 Therapeutic processes in OSG communication

Apart from the exchange of social support on OSGs, there is also evidence of other therapeutic factors at work (Weinberg, Uken, Schmale & Adamek, 1995). Self-disclosure is one of the key therapeutic features which has been found to occur alongside information and support communications (Winzelberg, 1997; Klaw et al., 2000). As demonstrated by Tichon and Shapiro (2003), self-disclosure is used both in the elicitation and provision of support in OSGs. Participants in an OSG for siblings of children with special needs used disclosure to attract social support. The disclosure of personal information and support has been found to be a maintaining factor in online conversations, whereas off-topic discussions seem to relate to a decline in OSG activity (Pfeil, Zaphiris & Wilson, 2010).

Researchers have shown that many of the therapeutic processes which occur in face-to-face support groups can also occur in OSGs, including empathy (Finn, 1999; Preece, 1999a, 1999b), problem solving and expressions of feelings and catharsis (Finn, 1999). Members help each other to normalise their illness experiences (Cranwell & Seymour-Smith, 2012) and provide a platform to discuss moral issues relating to illness (Bar-Lev, 2008). Members can also provide encouragement in the form of helping others to monitor their progress with health goals (Cranwell & Seymour-Smith, 2012).

Studies that have examined the extent to which a number of self-help mechanisms (originally identified by Perron, 2002) occur in OSG communication help illustrate the more common therapeutic processes occurring in OSGs. The most often reported self-help mechanisms found in these studies are sharing personal experiences, providing empathy or support and requesting information. Less frequently occurring mechanisms include expressing gratitude, creative expression, and making friendships and chit-chat (Haker, Lauber & Rössler, 2005; Perron, 2002; Malik & Coulson, 2011)

3.6.3 Data-driven analyses of online support communication

The research presented in the previous two sub-sections has focused on various deductive analyses of OSG communication. This research is valuable in terms of classifying and quantifying the occurrence of theorised communication processes (e.g., social support exchange and

self-help mechanisms) in OSGs. These studies, however, necessarily condense rich textual data from OSG communications in to pre-conceived theoretical frameworks and may miss some of the unique topics and processes which occur in OSGs as a result (Finfgeld, 2000). Inductive analyses of OSG communication have received less attention to date in the online support literature.

Data-driven qualitative approaches can be useful in delineating how OSG users interact online and in examining the key topics discussed in these groups. Such analyses have provided important information about the functions of OSGs for members, demonstrating both implicit and explicit needs for information (Barney, Griffiths & Banfield, 2011) and requests for information or recommendations on treatments, medication and services (Armstrong, Koteyko & Powell, 2012; Barney et al., 2011; Chen, 2012; Huber et al., 2010; Springer et al., 2011).

Other topics which participants have been found to discuss include coping with living with their illness and dealing with symptoms (Armstrong et al., 2012; Barney et al., 2011; Haker et al., 2005; Springer et al., 2011). Participants have also been found to use OSGs to disclose stigmatising illnesses (Barney et al., 2011). Some groups also feature discussions and encouragement on political activism related to the experience of living with an illness or disability (e.g., Peterson, 2009) or on ethical and philosophical debates about the illness (Springer et al., 2011).

Such analyses also provide information on how members support each other on these groups. Members tend to offer each other information, emotional support, personal experiences and recommendations (Armstrong et al., 2012; Chen, 2012; Cunningham, van Mierlo & Fournier, 2008; Greer, 2000; Springer et al., 2011). Specifically, members have been found to provide encouragement to others in terms of being resilient and staying positive (Attard & Coulson, 2012; Cunningham et al., 2008). Sharing similar experiences and demonstrating empathy have been found to be key processes allowing members to discuss taboo topics and build friendships (Attard & Coulson, 2012). By allowing opportunities for catharsis and support, groups can function to help validate members' emotions (Greer, 2000).

Data-driven analysis of OSG communication can also be used to examine under-researched aspects of OSG use. This may include, for example, the processes by which members join and integrate others to the online community. The analysis of message postings by Armstrong et al. (2012) provided an insight into how OSG members create legitimacy for their participation in a new OSG by describing their relationship to the illness in initial posts. This is similar to an investigation of OSG participation, using conversation analysis, by Stommel and Meijman (2011), where members' presentation of their diagnosis of an eating disorder worked as a legitimisation process when joining a group. New members have been found to receive multiple messages of support when they first join a group (Attard & Coulson, 2012). Participant introduction and welcome messages have also been found to be a significant part of the process of establishing and reinforcing group interactional norms (Peterson, 2009).

Following on from the experiences of newcomers to an OSG, Armstrong et al. (2012) found that members then created and maintained solidarity by noting similarities in personal experiences and making connections between members' experiences. Participants also emphasised the reciprocity of support exchange by showing gratitude to other members and demonstrating their own role in helping others. In terms of maintaining conversation activity, there was a distinction between those who wanted to use the board more socially, rather than instrumentally as a way of discussing purely condition-related issues. Social messages, however, often faded out, while messages on practical issues received more positive attention. This result is similar to findings from a study by Pfeil et al. (2010), where messages to an OSG for older people that involved disclosing personal information or exchanging support resulted in higher levels of subsequent messages, whereas off–topic conversations received fewer responses.

This type of data-driven inductive analysis of OSGs can therefore inform researchers about the nature of participants' information or support needs when using particular OSGs. It can also provide valuable information as to how groups develop and are maintained over time.

3.7 Psychosocial outcomes of OSG participation

Research on the content of online support communication can only provide limited information on how support may be perceived or received by members. Participants often report that OSGs have been helpful for them (e.g., Lieberman et al., 2003). However, definitive evidence of psychosocial benefits is lacking (Eysenbach et al., 2004). The following sections will present existing research evidence for the impact of online support participation on coping, empowerment and psychological health. Outcome research in this area is complicated by a number of factors, which will be discussed in the final part of this section.

3.7.1 Enhanced coping and empowerment

There are a number of theoretical reasons why OSG use may increase participants' ability to cope with health problems. Roter and Hall's (1997) patient-communication theory suggests that access to information (e.g., access to information from an OSG) may influence a persons' behaviour in relation to managing their health. Self-efficacy theory (Bandura, 1977) proposes that access to information may improve participants' confidence in their ability to manage their condition.

Self-reported outcomes of OSG participation suggest that members have found using OSGs to be an accessible way of finding advice on how to cope with, better understand, and manage an illness or condition (Buchanan & Coulson, 2007; Coulson & Knibb, 2007; Klemm et al., 2003; Leonard et al., 2004). Participants have reported valuing the experience of learning from others (Pfeil et al., 2009) and feeling better informed and supported through OSG participation (e.g., Han & Belcher, 2001; Han et al., 2008; Lieberman & Goldstein, 2006; Rodgers & Chen, 2005; Sharf, 1997; Shaw et al., 2000; Wiljer et al., 2011). OSG participants have also reported feeling empowered (e.g., Baum, 2004; Høybye et al., 2005; Malik & Coulson, 2008; Sullivan, 2008; van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008; van Uden-Kraan, Drossaert, Taal, Seydel & van de Laar, 2009), experiencing a sense of intimacy and belonging (Høybye et al., 2005) and feeling more optimistic about coping with their illness (Rodgers & Chen, 2005).

Specifically, in terms of the impact of OSG participation on health care service utilisation, participants have reported feeling more empowered to

make decisions about treatments or seek professional help for their illness (Buchanan & Coulson, 2007; Powell, McCarthy & Eysenbach, 2003). OSG users have also described feeling more confident in seeking additional professional opinions (Høybye et al., 2005) and preparing for medical appointments (Coulson, 2005; Shaw et al., 2000).

Some authors have demonstrated an impact of OSG use over time in longitudinal quantitative studies, in relation to health care utilization and health improvements. For example, a positive effect has been found for participation in an OSG for drug users, as participants in the OSG group were more likely than controls to remain in drug treatment at follow-up (Alemi et al., 1996). Gustafson et al. (1994, 1999) also found an impact of OSGs on health care utilization, in that those accessing online support for HIV/AIDS spent less time attending outpatient clinics and had fewer and shorter hospitalisations than control group members.

OSG participation may help patients by empowering them to deal with their health issues. While empowerment is still an ill-defined concept (Broom, 2005b; van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008), Sharf (1997) has suggested that empowerment in an OSG setting is dependent on how participants perceive the information and support available online in terms of helping them to develop the knowledge, skills, attitudes and awareness needed to make informed decisions. Some authors (e.g., Broom, 2005b) suggest that empowerment is experienced differently by each individual and may mean different things for different individuals.

Van Uden-Kraan, Drossaert, Taal, Shaw et al. (2008) examined if, and in what ways, members felt empowered by taking part in an OSG for breast cancer, arthritis and fibromyalgia by interviewing 32 participants. The researchers distinguished between empowering processes (processes which occur during participation) and empowering outcomes (changes which result from participation). Evidence was found for a range of empowering processes, including the following: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others and amusement. Empowering outcomes identified by the authors were: being better informed; feeling confident in their relationship with their physician, their treatment and their social environment; enhanced acceptance of the disease; enhanced optimism

and feelings of control, self-esteem and social well-being; and collective action.

A number of authors have continued the investigation into empowering processes and outcomes using questionnaires based on the original interview study by van Uden-Kraan, Drossaert, Taal, Shaw et al. (2008) and the empowering processes and outcomes questionnaire developed by van Uden-Kraan et al. (2009). Evidence has been found for the existence of all of the included empowering processes and outcomes, and feeling better informed and experiencing enhanced social well-being were found to be the most commonly occurring empowering outcomes across a number of OSGs (Bartlett & Coulson, 2011; van Uden-Kraan et al., 2009). Greater participation in an OSG for HIV has been associated with an increased likelihood of experiencing a number of empowering processes (Mo & Coulson, 2012).

3.7.2 Impact on psychosocial health

Qualitative research studies have been particularly useful in elucidating the positive impact of OSG participation on group members' psychological well-being. These benefits include reduced feelings of isolation (Høybye et al., 2005; Wiljer et al., 2011), reduced uncertainty regarding prognosis and ambiguous painful symptoms (Høybye et al., 2005) and reduced distress and better mood (Rodgers & Chen, 2005). Participants have reported appreciating the opportunity to share experiences and feelings (Han & Belcher, 2001) and have found participating in such groups to be a cathartic process (Buchanan & Coulson, 2007). Some members have reported feeling better understood by OSG members (Coulson & Knibb, 2007), feeling secure enough to reveal personal difficulties within the group (Buchanan & Coulson, 2007), having an increased availability of friends one can relate to (Johnson, Ravert & Everton, 2001) and feeling less isolated (Dunham et al., 1998; Flatley-Brennan, 1998).

Further self-reported emotional benefits include feeling supported (Vilhauer, 2009; Johnson et al., 2001; Lieberman et al., 2003), feeling more optimistic (Høybye et al., 2005; Rodgers & Chen, 2005; Zrebiec, 2005) and feeling less anxious (Coulson & Buchanan, 2007). Carers have also reported experiencing improved relationships with care recipients (Baum, 2004) and partners (Malik & Coulson, 2008). OSG participation has helped

some participants validate their illness experience, leading to increased confidence and acceptance of illness-related issues (Letorneau et al., 2012; Wiljer et al., 2011). OSG participation has also been found to increase positive coping affect (Seçkin, 2011).

Some quantitative longitudinal research has suggested beneficial outcomes of OSG participation. In a longitudinal evaluation of an online mailing list for parents of children who had been diagnosed with cancer, significant effects on parents' psychological well-being (i.e., depression, stress and anxiety) were found over the course of the four-month study (Bragadóttir, 2008). Beneficial effects of OSG participation have also been documented in a follow-up study of members of an OSG for people with diabetes (Barrera, Glasgow, McKay, Boles & Feil, 2002). Participants improved significantly on both a general measure of perceived support and on a diabetes-specific support scale after three months of participating in the intervention. A non-controlled, longitudinal study of an online breast cancer forum, led by professional facilitators, also found that members' scores improved in depression, post-traumatic growth and psychological well-being (Lieberman & Goldstein, 2005). Social isolation and loneliness were significantly reduced in a peer-moderated OSG for adolescents with asthma and allergies (Letourneau et al., 2012).

Without control groups in such studies, however, it is difficult to assess whether changes in outcome scores can be attributed to actual therapeutic changes as a result of OSG use (Lieberman & Goldstein, 2005). Indeed, a number of randomised control trials (RCTs) on OSGs have failed to show any impact of OSG use on psychological outcome measures (e.g., Freeman et al., 2008; Høybye et al., 2010; Owen et al., 2005; Salzer et al., 2010).

3.7.3 Effect of OSG participation levels

There is some evidence that greater participation in an OSG can lead to improved outcomes for participants. For example, Houston, Cooper and Ford's (2002) one year prospective study of members of a depression OSG found that participants who used the group more often were more likely to report resolution of depression. Similar patterns have been found in evaluation studies of other online groups, where increased participation has been related to greater emotional benefits (Cummings et al., 2002; Dunham et al., 1998).

OSG communication has also been examined using the expressive writing paradigm to examine the relationship between participation and psychological outcomes. According to the expressive writing paradigm, writing about stressful experiences (especially using a high level of emotional disclosure) can lead to the reframing of experiences, enhanced coping and better psychological and physical health outcomes (e.g., Pennebaker, 1993; Pennebaker & Seagal, 1999). Higher frequency of posting in some OSGs has been related to lower distress (Barak & Dolev-Cohen, 2006) and better coping (Tanis, 2008). Similarly, the level of insightful disclosure in participants' posts had a positive impact on breast cancer concerns and functional well-being in a breast cancer OSG (Lieberman, 2007), and has been related to improved emotional well-being and reduced negative mood (Shaw et al., 2008).

Emotional disclosure has not always been linked to positive outcomes, however. For example, Shaw et al. (2008) found a positive relationship between the use of first person pronouns in messages and negative emotions among participants. Disclosure of all types of emotions may not be related to positive outcomes. For example, Lieberman and Goldstein (2006) found that expression of anger in breast cancer OSGs was related to higher QoL and lower depression scores, whereas expressing fear or anxiety was related to lower QoL and higher levels of depression.

It is unlikely that the expressive writing paradigm can account completely for any potential benefits of increased OSG participation. OSG participation is a naturally dynamic conversation with other participants and this paradigm does not account for the support members may receive from others and offer to others, which may be an important part of any psychological benefits experienced. Indeed, those who are more satisfied with the support they received have been found to experience less stress (Wright, 1999). Those who offer higher levels of support to others have also been found to experience more positive outcomes (Kim et al., 2012).

Winefield (2006) found that those who posted frequently to an OSG were more likely to support others than seek support. These users also found this role satisfying due to the ability to help others. The helper therapy principle (Reissman, 1965) may apply to those who frequently provide

support to others, in that participants may personally benefit therapeutically from being able to help others to problem solve. Therefore, potential benefits of increased participation cannot be understood purely in terms of increased writing and self-disclosure.

3.7.4 Challenges to evaluating OSG participation effects

A number of systematic reviews have concluded that there is a lack of high quality evidence for the efficacy of OSGs (Eysenbach et al., 2004; Griffiths, Calear & Banfield, 2009; Hong, Pena-Purcell & Ory, 2012). Some authors have concluded that there is a lack of rigour in study designs (Hong et al., 2012) and others have called for more randomized controlled trials to be carried out in this area, in order to further develop the evidence base (Demiris, 2006; Griffiths et al., 2009; Klemm et al., 2003).

While RCTs may be desirable for experimental rigour, there are a number of reasons for the limited randomized controlled evidence for the efficacy of OSGs. One such factor is the variability in the frequency of OSG use by different participants within a study (Baker et al., 2010). This can complicate evaluation processes as not all participants will utilize the online support intervention in a uniform way. Attrition can also be a serious problem in online interventions. For example, Aarts et al. (2012) found attrition rates of between 16% and 68% in studies reviewed on internet interventions in infertility. Small sample sizes can also impact on the definitiveness of study results (Klemm et al., 2003; Vilhauer et al., 2010).

Conducting controlled trials of naturally occurring OSGs (i.e., those not designed for research purposes) is difficult, as researchers do not have the ability to randomize participants to intervention and control groups. Also, naturally occurring OSGs are in a state of constant change, as members join and leave at various times, making it difficult to evaluate the effects of participation over time (Lieberman & Goldstein, 2005). Recruiting participants from naturally occurring OSGs can also prove challenging, due to the researcher's position as an outsider to the group (Lieberman & Goldstein, 2005). The evaluation of these groups is therefore a more challenging process, compared to evaluating OSGs designed purely for research purposes.

As identified in the systematic review of OSGs by Eysenbach et al. (2004), it has been difficult to evaluate the efficacy of online support groups as OSGs have often been evaluated as part of a multi-component intervention, or they have included some element of professional input. Many earlier studies evaluated multi-component interventions which involved information services and decision making tools, as well as peer support components, such as the Comprehensive Health Enhancement Support System (CHESS) used for those with breast cancer and HIV (Bauerle Bass, 2003; Boberg et al., 1995; Gustafson et al., 1994; Gustafson et al., 1999; McTavish et al., 1995; Shaw et al., 2000) and ComputerLink, a closed computer system containing similar features (Bass, McClendon, Brennan & McCarthy, 1998; Brennan et al., 1995; Flatley-Brennan, 1998).

In multi-component interventions, it is inherently difficult to pinpoint the cause of any improvements in psychological outcomes due to the confounded nature of the interventions (Duffecy et al., 2012; Eysenbach et al., 2004; Gustafson et al., 2001; Vilhauer et al., 2010). Similarly, in studies with trained health professionals directing the conversations within a group, it is difficult to know whether benefits are due to peer support or professional moderation. There is a need, then, for studies which evaluate purely peer-to-peer OSGs, which occur outside of complex research study interventions within a naturalistic setting.

3.8 Research aims

The purpose of the research reported in this thesis is to holistically examine the experience of using an OSG for NMDs. As noted by Coulson et al. (2007), there is limited research published on the experiences of participants using OSGs for rare diseases, such as NMDs. This research aims to address this gap in the literature.

It is likely that people affected by rare diseases such as NMDs have different concerns to those who are affected by more common chronic illnesses. Similarly, it is likely that, for progressive conditions which have no current treatment or cure, such as NMDs, the focus of OSG conversations and interactions may significantly differ from illnesses where treatments are available. There is currently limited research examining the development of new naturally occurring (rather than

professionally-led) OSGs. The current research also aims to address this gap in the literature, taking a naturally occurring OSG as its focus. In keeping with these aims, the two empirical elements contained in this thesis aim to understand the role of a new, naturally occurring OSG for NMDs (encompassing a range of rare diseases) in supporting people living with these disorders.

Adopting a qualitative approach, this research aims to develop an understanding of: members' motivations for using the OSG in question; factors related to members' use of the group; and any personal impact of participation. The analysis of members' interactions during the initial stages of the group's development will be presented in the first empirical thesis component, in order to gain a unique insight into how this new OSG was used by members (Chapters 5 to 7).

This first analysis will then be complemented by an interview-based study, which will examine: the context through which members chose to take part in this OSG; factors which influenced their engagement with the group; and any personal impact that use of the OSG had for them (Chapter 8). Included in this interview element is the experience of one of the OSG moderators. Moderator experiences have only recently been explored in any depth (e.g., van Uden-Kraan, Drossaert, Taal, Seydel & van de Laar, 2010). Moderators are likely to play a key role in setting up and maintaining activity in new OSGs. Therefore, understanding their motivations and experiences can provide another important insight into OSGs. By including a moderator in the interview element, this thesis aims to garner an exploratory insight into OSG moderator experience.

The personal impact of taking part in an online support group for people with NMDs has not yet been studied. This thesis aims to address this gap in current understanding. As outlined in Chapter 2, having a neuromuscular disorder has a profound impact on the lives of those affected. There are also particular challenges in terms of gaining support from others, due to the disabling and rare nature of these disorders. Because the use of OSGs by people affected by NMDs is an under-researched phenomenon, an exploratory, qualitative approach is well-placed to explore it. By examining this under-researched area, important insights can be gained as to the viability of online support in helping

people with NMDs to deal with the impact of rare, genetic, and often-progressive diseases. Given the disabling nature and rareness of NMDs, it is likely that online support would function as an important social outlet and information resource for NMD sufferers in particular. Those with limited mobility and those dealing with conditions about which little is known would seem particularly inclined toward the social and information-rich context afforded by new OSGs. Thus, this research into the area is timely and significant.

Chapter 4: Message Posting Analysis Methodology

4.1 Introduction

An important method of enquiry into the role of health-related OSGs has been the analysis of communication between members on such groups. The content of messages posted to online groups provides a rich source of data about the utility of OSGs for members. In order to evaluate the role of OSGs for people affected by NMDs and their carers, the first empirical study in this thesis sought to examine the thematic content of a new OSG for people affected by NMDs.

In this chapter, a description of the advantages and disadvantages of using message postings to examine the role of OSGs will be presented. This will be followed by an overview of the ethical issues arising from analysing message postings on an OSG. A summary of some of the qualitative methodologies which have previously been used to examine the content of message postings on OSGs will then be presented. This general discussion will lead into a description of the methods used in this particular study.

4.2 Message posting analysis – advantages

Analysis of message postings to OSGs has been described as a passive (Eysenbach & Till, 2001) or non-reactive (Murray & Sixsmith, 2002) research method. Public profiles or public groups allow researchers to potentially access large amounts of data on a wide range of experiences, which can be investigated with relative ease and minimal expense (Wilkinson & Thelwall, 2011). The analysis of information communicated online can help researchers systematically examine patient and health care provider needs and concerns, as well as values and preferences related to patient's health and health care services (Eysenbach & Till, 2001). The study of message postings to online groups has a number of potential benefits in terms of understanding the content of discussions and the dynamics, processes and patterns of communication in such groups.

Message postings are unique sources of data as they are recordings of naturally evolving conversations between participants, which are not elicited or affected by a researcher and are not as polished as traditional written documents (Murray & Sixsmith, 2002). Such data have been described as authentic and natural, rather than forced and formulaic (Robinson, 2001).

Due to the lack of researcher involvement in the creation of data, these research methods may be less prone to biases such as social desirability (Malik & Coulson, 2008) and may make the views of the group members more salient (Murray & Sixsmith, 2002). This method of collecting data may be a less intrusive way to collect information about sensitive topics for those who may not be comfortable relaying experiences to a researcher (Murray & Sixsmith, 2002). Message posting analysis may also be preferential in terms of incorporating a wider range of views, including the views of those who may not be represented in other types of participatory research studies, due to sensitive health problems, time issues, etc. (Sixsmith & Murray, 2001; Murray & Sixsmith, 2002; Robinson, 2001; Seale, Charteris-Black, MacFaralane & McPherson, 2010).

4.3 Message posting analysis – limitations

There are, however, some disadvantages of analysing message postings in terms of understanding group members' experiences. For example, the experiences of those who lurk, or do not post messages, will not be accounted for in this type of research (Murray & Sixsmith, 2002; van Uden-Kraan, Drossaert, Taal, Seydel et al., 2008). The conversation process may also be influenced by group moderators or more dominant contributors (Murray & Sixsmith, 2002), which may make some participants' views more salient than others in the analysis. The analysis of message postings also provides limited information about the outcomes of participation, participants' motivations for taking part or their evaluation of their online experiences.

Robinson (2001) suggests using internet data as an on-going part of a triangulated process of research in order to build a trustworthy analysis. Similarly, Murray and Sixsmith (2002) suggest using message posting analysis along with other methods such as interviews to try and

incorporate the experience of all those using the group and not just those who post messages to the group. In this thesis, message postings analysis is supplemented with an interview-based research study which enables further clarification of the motivations, experiences and outcomes of taking part in an OSG for NMDs for group members, including those who do not post messages.

4.4 Ethical debate

There has been considerable debate among social scientists about the ethical issues surrounding the use of online message postings or archived message postings for qualitative research. A cornerstone of this debate has been about the ethical principle of informed consent. Guidelines for psychologists generally exempt them from needing to gain informed consent for research which takes place in a public space and involves naturalistic observations (American Psychological Association, 2010). The British Psychological Society (2009) Code of Ethics and Conduct suggest that observational studies should be restricted to settings where participants may reasonably expect to be observed by strangers. However, the virtual context is not considered in some of these guidelines for researchers (Bowker & Tuffin, 2004), leading to debate about the nature of public and private spaces on the internet.

There are a number of reasons why gaining consent to analyse messages posted to an OSG may be problematic. Any consideration of gaining consent from participants when analysing online group postings has to consider the potential effect that disclosing the research study objectives will have on group dynamics and processes. Researchers must carefully consider the level of intrusiveness that their research may have on the online group (Waskul & Douglass, 1996). There is a possibility that disseminating research objectives to participants may harm members' ability to feel safe to disclose information within the OSG (King, 1996).

There are also practical limitations in terms of how researchers would actually gain informed consent from OSG members to analyse their communication. Options for obtaining consent include e-mailing the group, giving people the opportunity to withdraw from the group, or asking retrospectively for permission to use postings (Eysenbach & Till,

2001). The first approach could affect group dynamics or participation, while the latter approach may prove less intrusive, but potentially time-consuming and difficult (Sharf, 1999). As members join and leave groups in a fluid manner, this makes the task of gaining informed consent from all members difficult (Eysenbach & Till, 2001; Waskul & Douglass, 1996; Sixsmith & Murray, 2001). Similarly, contacting participants may be complicated, for example, if contact details such as e-mail addresses are no longer valid (Eysenbach & Till, 2001). Removing selected participants from an analysis due to a lack of permission to use postings may also mean that the analysis process becomes more difficult as the rich, conversational aspect of the communication could be lost if voices are excluded (Flicker, Haans & Skinner, 2004).

Many researchers have argued, however, that observational research such as the analysis of online communication does not require informed consent. Wilkinson and Thelwall (2011) argued that publicly accessible postings are considered public documents. Similarly, Walther (2002) argued that using participants' posts to online groups is similar to traditional archival research. Due to the lack of participant interaction, and the ready access to posts, Walther suggests that this type of research does not need to be considered by ethics boards as human subjects' research.

Instead of focusing on informed consent, researchers have focused on ways to establish the level of privacy of online groups as an indicator of the appropriateness of analysing communication within certain groups. Eysenbach and Till (2001) suggest three factors to consider when assessing the potential privacy of an online group – size, member-only access and group norms. Although difficult to assess actual user numbers, a forum is more likely to be considered private if it has a smaller membership (Eyensbach & Till, 2001; King, 1996; Robinson, 2001; Waskul & Douglass, 1996). If a subscription is required to participate and read messages, then the group is more likely to be considered private (Mayer & Till, 1996). Eysenbach and Till (2001) also suggest that researchers should pay attention to group norms in order to evaluate the potential privacy level of a group. For example, introductory messages or FAQ sections may provide ground rules on membership or the use of message data by researchers. Waskul and Douglass (1996) also suggest that the

specific nature of a group and the topics discussed within the group can also give an indication of the perceived privacy of a group.

A number of steps can be taken to help protect the identity of communicators in online groups. The British Psychological Society (2007) guidelines for ethical practice in online psychological research suggest that researchers should avoid using quotes which are traceable to an individual's posting via a search engine, unless a participant explicitly consents to this. Similarly, usernames employed by members in online groups should be treated with the same ethical respect as a researcher would treat a person's real name. The address of the website or discussion forum from which data are gathered should not be published alongside any analysis of communication.

The British Psychological Society (2007) guidelines have been echoed by a number of researchers who recommend protecting individuals by not publishing names, usernames, e-mail addresses and the virtual location of the group (Colvin & Lanigan, 2005; Murray & Sixsmith, 2002; Sixsmith & Murray, 2001; Waskul & Douglass, 1996). As some search engines are able to index postings from online groups, securing anonymity using pseudonyms may not be sufficient, as phrases which link back to a participant's virtual location may be searchable (Bowker & Tuffin, 2004). Therefore, not using verbatim quotes may also be an option to protect anonymity (Sixsmith & Murray, 2001).

4.5 Analytic approaches

A number of different approaches have been used by OSG researchers to examine the communicative processes of group members. Each approach has associated benefits for different research aims. A popular approach to analysing messages has been deductive thematic or content analyses. Many researchers have, for example, used versions of the Cutrona and Suhr (1992) social support framework to guide analysis of message postings across OSGs for a wide variety of health issues (Braithwaite et al., 1999; Coulson, 2005; Coulson et al., 2007; Coulson & Greenwood, 2012; Evans et al., 2012; Mo & Coulson, 2008). Similarly, researchers have developed and used coding frameworks based on self-help mechanisms or processes developed from traditional research on mutual support groups

(Haker et al., 2005; Finn, 1999; Perron, 2002; Malik & Coulson, 2010, 2011). Other researchers have also developed wider coding schemes to analyse messages to OSGs (e.g., Klaw et al., 2000; Klemm et al., 1999; Salem et al., 1997; Winzelberg, 1997).

The deductive analytic approaches outlined above allow researchers to examine whether or not certain theorised processes or themes occur and to what extent these occur. The quantification of these processes or themes allows comparison across studies and across different types of OSGs, thus allowing examination of similarities and differences between groups (e.g., Klemm et al., 1999).

In contrast to theory-driven or deductive analytic approaches, some researchers have employed a data-driven, inductive approach to message postings analysis. These analyses have provided unique insights, both into how conversations are developed and maintained online (e.g., Armstrong et al., 2012) and into the thematic content of individual OSGs, identifying issues which may be unique to the particular health issues under consideration (e.g., Attard & Coulson, 2012; Blank & Adams-Blodneiks, 2007). This type of research has been particularly useful for highlighting information or support needs and particular issues faced by members of different types of OSGs (Hoch et al., 1999; Mahoney, 1998; Mendelson, 2003; Springer et al., 2011).

Inductive research approaches allow researchers to develop a unique set of themes, which are grounded in the data of the specific type of OSG being studied. This allows researchers to uncover aspects of the OSG experience that may not be captured using pre-defined theoretical frameworks. A number of different inductive analytical approaches have been used in the analysis of OSG communication, such as phenomenological analysis (e.g., Sullivan, 2003, 2008; Gavin et al., 2008; Mulveen & Hepworth, 2006), grounded theory (Gooden & Winefield, 2007; Haas et al., 2010) and inductive thematic analysis (e.g., Attard & Coulson, 2012). Inductive analysis has also been used to supplement deductive approaches, to identify potential disadvantages of OSG use (e.g., Coulson & Greenwood, 2012) and to identify further potentially positive group interaction processes (Coursaris & Liu, 2009).

Linguistic approaches such as discourse and conversation analysis have also been used to examine some of the processes by which conversations are created and maintained online. For example, Cranwell and Seymour-Smith (2012) demonstrated how monitoring discourse (e.g., members of the group enquiring about each other's progress) acted as a social support mechanism on a bariatric surgery weight-loss support group. Stommel and Meijman (2011) used conversation analysis to examine the discursive processes involved when newcomers join a new OSG and how members establish legitimacy. Such approaches are useful when researchers are interested in the linguistic construction of experiences online, rather than the thematic content of members' experiences. Computerised text analysis has also been used to examine the emotional content of message postings (e.g., Han et al., 2008). While computerised approaches may indicate the emotional content of OSGs, the context of communication is lost.

4.6 Method

4.6.1 Study aim

The aim of this study was to examine the thematic content of communication by members on a new OSG for people affected by NMDs. By examining the communication between members on this OSG, it was hoped that an insight would be gained into why people accessed the group, how the support group was used by members and the key issues discussed by members.

Research on communicative processes in the development stage of a new OSG is rare. Aakhus and Rumsey (2010) argue that there is a need for further research on how online communication is constituted and maintained in such groups. Therefore, the researcher chose to analyse messages from the beginning of a new group, to gain an understanding of how the group developed over time. Similarly, very little research has been conducted on online support communication in rare diseases. It was hoped that this research would also capture aspects of the online experience unique to members who have uncommon conditions.

4.6.2 Data collection

Data were collected from naturally occurring conversations on a new publicly-accessible, U.K. based message board, on an OSG for people affected by NMDs. All message postings (n= 1,951), were collected from the first 5 months of messages posted to the forum and were indexed into a catalogue, so that messages could be analysed in the context of message threads or conversations. These messages were the product of 270 distinct conversation threads. It was important that message postings were analysed holistically, in the context of conversation threads, to aid the interpretation of data (Sixsmith & Murray, 2001). The average length of a message posting was 113 words.

There were a total of 144 unique users who had posted to the OSG identified in the extracted data. Each of these users contributed between 1 and 330 messages each (average number of messages per user = 13). From the available cues, it was ascertained that 54.2% of users were female (n=78) and 28.5% were male (n=41). The gender of 17.4% of users (n=25) was unclear. Female posters contributed 55.4% of messages (n=1,081), while 26.6% of messages were posted by males (n=519). A further 18% of posts were contributed by those whose gender could not be discerned (n=351).

From the available indicators in the message posts, it was possible to establish that carers or family members (n=30 users) made up 21% of the posters, while they contributed only 3.7% of the message posts (n=73 posts). Individuals who had NMDs made up 47.2% of the users identified in the sample (n=68 users) and they contributed 79.9% of the message posts (n=1,558 posts). Charity staff members made up 11.8% of the identified users (n=17) and contributed 11% of the posts (n=214). Other members such as researchers, paid caregivers and advertisers made up 5.6% of the user group (n=8), contributing 5.6% of the message posts (n=20). There was not enough information to categorise 21 users (14.6%) in this way. These remaining users contributed 4.4% of the message posts (n=86).

4.6.3 Ethical considerations

A number of ethical considerations were taken into account in designing this study, in line with the issues presented earlier in this chapter. A large

OSG was chosen, as this was more likely to be considered a public group. The OSG used for the study had a membership of over 600 members at the time data were collected, with approximately 300 to 400 message postings per month. The OSG chosen for this study had a discussion board which was viewable by the public, without the requirement of a membership log-in. Therefore, in line with other similar studies (e.g., Coulson, 2005; Malik & Coulson, 2010), it was not deemed necessary to gain informed consent for the analysis of message postings. Furthermore, gaining informed consent would also have proven impractical due to the large number of members of the online group and may have disturbed the discursive processes on the newly formed group.

Efforts were made, however, to protect the identity of members of the online group by only using short extracts from their communication to illustrate themes in all write-ups of the study. Furthermore, all potentially identifying information (e.g., name, age, type of diagnosis etc.) for each participant and the group as a whole was removed from extracts used. Pseudonyms were used to protect participants' identities and online usernames. The name of the OSG is not included in the thesis.

The study also received ethical approval from the researcher's internal ethics committee at the Institute of Work, Health and Organisations at the University of Nottingham (see Appendix 1).

4.6.4 Analysis

Due to the lack of existing literature examining communication between members on an OSG for people affected by rare disorders, data were analysed using an exploratory, inductive, data-driven approach. This allows potentially unique aspects of users' experiences to emerge. Thematic analysis was chosen as appropriate for the data for a number of reasons.

Thematic analysis can provide detailed qualitative accounts of the particular phenomenon of interest, allowing the researcher to examine salient issues or patterns across a qualitative data set. It enables the researcher to identify themes that occur in the data in order to describe, organise and report patterns in the material (Braun & Clarke, 2006). The generation of themes across data sets is not particular to thematic

analysis, with many of the major qualitative methods involving the "thematizing" of data (Holloway & Todres, 2003, p. 347; Ryan & Bernard, 2000). However, unlike most major qualitative analytic approaches in psychology, thematic analysis is not married to a specific epistemological perspective. Indeed, Braun and Clarke (2006) argue that qualitative methods for psychology fall into two camps: those that are tied to specific epistemological or theoretical underpinnings (e.g., Grounded Theory, Interpretative Phenomenological Analysis and Discourse Analysis), and those that are not (e.g., thematic analysis). Thematic analysis is described as applicable across a range of epistemological positions (Braun & Clarke, 2006). Therefore, a thematic analysis approach offers a theoretical freedom that is unavailable in other approaches and that is appropriate for the current thesis. The empirical elements of this thesis take a phenomenological perspective. Thematic analysis is amenable to use in conjuntion with a range of epistemological lenses, therefore it aligns with the phenomenological approach adopted here.

Phenomenology is a theory of knowledge that takes real-life, moment-to-moment understandings of the world as its primary unit of study. Based on the writings of Husserl and Merleau-Ponty, the phenomenological epistemology focuses on people's immediate, everyday experiences of their reality – their perceptions and feelings – in order to garner a deeper understanding of the phenomenon at hand (McLeod, 2001). The OSG message posting data presented here are compatible with a phenomenological approach, given that it accesses the everyday, often spontaneous thoughts and feelings of the message posters. The message postings were therefore analysed for key themes using thematic analysis (Braun & Clarke, 2006) in which a phenomenological perspective was adopted (Osborne, 1990).

The analytic process followed guidelines described by Braun and Clarke (2006). Initial analysis involved reading and re-reading the entire message posting data set several times. This was an "active" reading, in which the researcher continuously made notes on initial impressions of and emergent patterns in the data (Braun & Clarke, 2006, p. 87). This reading phase was given particular attention given that the author did not transcribe the data. Because transcription can represent an important phase in the researcher's acquaintance with the raw data, this reading

phase was repeated many times, allowing data saturation to develop over time (Bird, 2005; Ely, Vinz, Downing & Anzul, 1997).

Braun and Clarke (2006) outline two approaches to this initial reading phase: one in which the reading is informed by theory and interprets data in relation to theory; and a converse approach in which the data set is the sole source of meaning. In the current research, the reading phase would be more accurately described as data-driven with a theoretical undertone. Given that the author had engaged with relevant research prior to data analysis, becoming exposed to relevant theory, initial readings of the data may have been coloured to a minor extent by this prior knowledge. However, the analysis remains rooted primarily in the data. The commitment to the message postings as a primary source of understanding is displayed in the data-driven process of thematic analysis detailed below.

After the initial reading phase had been completed, the code-generation phase of analysis began. This second phase involved organising and interpreting the data at a basic level, breaking it down into workable segments. The entire data set was coded manually. The author assigned descriptive/interpretive codes to as much of the data as possible, often assigning multiple codes to the same segment. At this point, the researcher was involved in fleshing-out as many interpretations of the text as possible and, in this respect, inconsistencies in the data were coded as readily as those that followed apparent patterns. These codes were collated and an exhaustive list was made of all codes.

The next analytic step refined this large index of codes. Each code was written on a separate, small piece of paper and sorted into "theme-piles" (Braun & Clarke, 2006, p. 89). This process was not linear in nature, often requiring the researcher to rework and rethink thematic groupings. It was also recursive in that codes were sourced back to the data from which they were derived, in order to ensure analytic rigour and connection with the data. Not all of the codes naturally fit into a thematic category and these codes were sorted into a 'Miscellaneous' theme-pile. At this point, the major theme-piles were identified, as well as smaller piles that were related to but not subsumed by each other. An effort was made, at this stage, to work the 'Miscellaneous' codes into the theme-piles, while

remaining open to new thematic formations. The thematic configuration at this point formed the final themes and sub-themes that are described in the analysis below.

A final analytic step involved further refining of the themes and their sub-themes. The researcher referred back to the data again, to ensure that the raw material fed in to the emergent codes, sub-themes and themes in a consistent way that was true to the original posting material. It was also ensured that each theme and sub-theme comprised enough raw data to warrant a theme or sub-theme. At this stage, a thematic map of the analysis was drafted, including a list of themes, sub-themes and codes within the sub-themes (as per Braun & Clarke, 2006; see Appendix 2).

The final analytic step focused on naming the themes and sub-themes in a way that described the "essence" of what they comprised (Braun & Clarke, 2006, p. 92). Here again, the original data were consulted in order to reflect the raw material in the theme and sub-theme names.

Three themes form the bases for the following three empirical Chapters, 5 to 7. These themes are presented, along with a discussion of the implications of these findings. These three themes and the Chapters that describe them are entitled: 'Connecting and Sharing'; 'An Understanding Audience'; and 'Recognition and Awareness'.

Chapter 5, 'Connecting and Sharing', will discuss themes related to the development of the group and its membership. Chapter 6, 'An Understanding Audience', will present themes regarding how participants used the forum in relation to coping with symptoms and managing their condition. Themes that contained a particular focus on the social aspects of the forum and the social aspects of living with a NMD are presented in Chapter 7, 'Recognition and Awareness'.

Chapter 5: Message Posting Analysis
Connecting and Sharing

5.1 Introduction

This chapter is the first of a set of three that present the results of the message posting analysis component of this thesis. The over-arching theme that describes the data presented in this chapter is 'connecting and sharing'. As the data consisted of the first 5 months of messages posted to a new OSG, an important element of the online coversations related to how members introduced themselves and established connections in the early stage of the group's development.

The three themes presented in this chapter outline how these connections were formed. 'Establishing common ground' describes how communication was initiated and maintained by members during the introductory phase. 'Sharing diagnosis experiences', a theme that occurred frequently as participants introduced themselves, describes the issues members faced in relation to getting a diagnosis. 'Sharing diagnosis support' describes how members provided support to those newly diagnosed or those struggling to get a diagnosis. Each theme will be presented in turn.

In the included message posting excerpts, square brackets (i.e., [ ]) are used to denote where identifying information has been removed to protect participants' identities. Where a piece of transcribed text has been removed for brevity, this is indicated by a double ellipsis (i.e., ……). It should be noted that some quoted extracts contain typographical errors, and these have not been corrected. The terms 'message board', 'discussion board' and 'forum' are used interchangeably to refer to the publically accessible message posting function of the OSG. These conventions apply throughout Chapters 5 to 7.

5.2 Establishing common ground

The theme 'establishing common ground' is concerned with how members moved from introducing themselves to connecting with others who had similar experiences. This theme also encompasses how members integrated and welcomed one another into the new group. The final component of this theme describes how members developed and communicated a sense of common purpose about the potential of the group to be an informative resource, as well as a welcoming and fun place to share experiences.

5.2.1 Disclosing personal information

Group members most often introduced themselves on the forum by disclosing personal information. This type of information included descriptions of their age, diagnosis or carer status, number of children, and their relationship status. Members also often described their current or past occupations, their qualifications and their hobbies or interests. A typical introductory paragraph is included below:

> Hello. I'm a [age] year old father, husband and all round bad son-in-law (you have to annoy someone) who shares a body with [type of muscle condition].....I work in [job area] (meaning not a lot but it sounds impressive), living in [place name]. I have 3 children......who are cared for on a day to day basis by my loving and fantastic wife.

5.2.2 Connecting with similar others

Forum participants often specifically stated their wishes to connect with others who had similar experiences to them, as part of their introductory posts. Some people sought connections with others who had similar types of NMD:

> I've just joined and was wondering if there is anyone else here with the same condition as myself. I have been told it's rare and I thought it would be good to speak to anyone who has any knowledge of this condition.

Apart from the desire to connect with members with similar NMDs, other members expressed a wish to connect to those that were in a similar stage of seeking a diagnosis:

> So I continue to have an undiagnosed Neuromuscular Condition, I
> am no longer looking for a diagnosis……I would be interested in
> hearing from anyone in a similar position.

When replying to new participants' introductions, other members used
this opportunity to note similar personal details or experiences and to
initiate further conversations with new members:

> I have [NMD type] too as well as a few other members.

> Reading your post bought back loads of memories for me! I too have
> [NMD type].

Members did not necessarily need to have the same condition as others to
note similarities between experiences, as some reported similar symptom
experiences despite different NMD diagnoses:

> I have a slightly different strain but almost similar effects.

The purpose of trying to connect with similar others seemed to be a desire
to discuss and share similar experiences:

> This is my story and I would like any one to talk and share who have
> also the same difficulties.

In addition, some participants discussed the desire to learn from other
members' similar experiences. For example, one carer discusses why she
would like to hear from others who are affected by her sons' condition.
She would like to know more about what the likely progression of this
condition:

> I struggle with what the future may hold for my precious boys and I
> would be grateful of any stories of early childhood and when
> symptoms started etc.

Existing members also helped to support the development of connections
between members with similar backgrounds by helping them to identify
others who were in a similar situation, such as those with similar
diagnoses. While this was not always possible initially when the group
was new, offers were made of connecting members with others with
similar conditions once the group membership grew:

> We will do our best to connect you with fellow [condition type]
> people as they join us.

While members sought and received contact from others on the basis of descriptions of their conditions, or their family members' conditions, they also connected in ways unrelated to their muscle condition, such as hobbies and interests:

> I thought I would be a bit different and tell you about the things I get up to beyond my condition.

Some members initiated discussion about their hobbies and interests by starting threads specifically related to their past-times, such as reading or visiting the cinema:

> I love going to the cinema. I'm a huge film fan......what do you like? What have you seen lately?

Others initiated conversations by noting similar interests:

> Like you I always led an active life and have enjoyed hiking.

By noting these similarities, members were often able to initiate further conversation and question each other about these hobbies or interests.

> Do you support any particular team/driver? I'm a [team name] gal.

5.2.3 "Make yourself at home"

Common ground was also established through the promotion of a welcoming environment to new members by existing users, particularly by forum moderators. This helped establish the forum as a 'place for everyone'. New members were often greeted with a welcome message that expressed happiness that the member had joined the group, or interest in the member's posts:

> Glad you popped by to say hi.

> Really enjoyed reading your stories.

Members also encouraged new participants to enjoy their time on the forum and feel comfortable in their use of it:

> Hope you have fun here.

> Make yourself at home.

New members were actively encouraged to become part of the community, through members expressing interest in hearing more of their stories or through receiving general encouragement to use the forum for topics related or un-related to NMDs:

> It would be great to hear more of your story some time.

> Post away with anything that is on your mind, whether it be the biased judging on Strictly Come Dancing, issues regarding your [condition type] life experience or concerns following the latest Government (dis)incentives.

Existing members also helped welcome and anchor newcomers into the group by noting the availability of support from other participants in the group. New members were encouraged to ask questions and were assured of the friendliness and helpfulness of others:

> We're a friendly bunch here.

> I'm happy to answer any questions if anyone want to PM me.

They were also signposted to any relevant additional sources of information or support:

> And if I can't answer your questions, I'll do my best to point you in the right direction.

Existing forum users assured new members that there would generally be others on the forum who had been through similar experiences and who could offer assistance:

> There is usually someone that can help or that has been through a similar experience.

Similarly, new members were pointed towards the guidance available on the OSG to help them to understand how to use the forum features:

> There are some "How to" guides in the 'hints and Tips" section, if you get into difficulty, please please do let me know, I need a guinea pig!

In response to the welcomes they received, new forum users often expressed their enthusiasm about being involved in the group. They also noted that they enjoyed meeting new people and expressed gratitude for the warm welcome:

> It's really nice to be here, everybody is so welcoming.

> Thank you for the welcome.

New forum users were often complimentary of the people they met on the message board, and the open sharing of information. They expressed how they were glad to be involved:

> Everything here is a good read for me.

> This seems like a great place with great people.

> I am glad to have found a site I can pop on to and ask questions.

5.2.4 Sharing aspirations for community development

Finally, in terms of creating a sense of common ground between members, both new and existing members expressed their aspirations about how they would like to see the group develop into a friendly, fun, informative and supportive resource for its members. Members expressed a keen interest in seeing how the forum developed:

> It's still early days but we're really looking forward to seeing how it develops.

One particular idea that multiple members mentioned was the wish to develop a community of expertise through the group, making it a "powerful resource" for its members:

> And that's what [group name] is all about, none of us know everything there is to know about muscular dystrophy, but we're all experts in our own little ways and together we've got lots of useful knowledge and interesting stories.

As well as hoping the forum would become a good information resource, members also expressed hopes for the development of a social and fun group, "a great place to hang out". Members expressed enthusiasm about getting to know others:

> I am looking forward to being part of this community and getting to know you all.

Some members particularly valued the opportunity to connect with people who readily understood their situation:

> It will be nice to chat to people who understand the 'niggly' things without huge explanation.

Other forum users specifically mentioned that they hoped to make friends through joining the forum:

> I would like to widen my circle though so thought I would give this site a go.

In terms of members' aspirations for a fun and social forum, as discussed previously some members started threads based on more social

discussions such as hobbies and interests. Similarly, the group moderators also initiated specific threads on jokes, games, pet photographs, etc.:

> Post pictures of your pets or if you don't have any your favourite cute animals. Here's one of my cats, [pet's name]......he's behind you!

These initial posts by moderators helped to initiate conversation threads that were unrelated to NMDs. These posts reflected the aspirations of moderators and members for developing a social environment.

5.3 Sharing diagnosis experiences

A common topic on the forum was sharing of diagnosis experiences. These types of conversations often occurred early on in members' postings, when they started describing their particular condition. Although there was considerable variation in terms of time since diagnosis, many had experienced delays in getting a diagnosis. Members shared a variety of feelings with regards to their diagnosis experiences, including both negative emotions as well as the positive experience of relief when they received a diagnosis.

5.3.1 Introducing relationship to NMDs

As mentioned earlier, forum users often introduced themselves through describing their particular type of NMD diagnosis or their family member's diagnosis. This was sometimes followed by a description of how the condition affected the member. For those who mentioned that they did not have a diagnosis, they sometimes described the most recent suggestion from doctors about what their condition might be, or they simply described how their condition currently affected them:

> My son is [age] and has an undiagnosed [condition type] affecting his legs and arms mostly.

Members' diagnoses were highly variable in terms of the different types of muscle disease they or their family members were affected by. Time since diagnosis was also variable, as some members had been diagnosed since childhood while others had been undergoing the diagnosis process more recently:

> I was diagnosed at 8yrs old.

> I have been recently diagnosed as suffering from [disease type].

5.3.2 Diagnostic delay

Despite differences in members' type of diagnosis, the time since diagnosis, and the fact that some members were still waiting for a diagnosis, a common theme of 'diagnostic delay' emerged from their description of their diagnosis process experiences. Reasons for delayed diagnosis were multi-faceted, ranging from factors which members attributed to their own personal reactions to their initial symptoms, to issues related to delayed recognition of symptoms by health professionals, to experiencing changing diagnoses over time and experiencing delays in access to genetic testing procedures or results.

Some members who had experienced a later onset of their NMD discussed personal factors which they felt contributed towards delayed diagnosis. These factors included a lack of realisation of the abnormality of some of the symptoms they were experiencing, especially at first when symptoms may have been less severe or pronounced. For example, one member described how he used to feel proud of his large calves, only to later discover that this was a symptom of his condition:

> Instead of them (calves) being something to be proud of, it was pseudo hypertrophy, one of the indicators of my condition.

For others, personal factors such as denying their symptoms influenced their delay in getting their symptoms checked out:

> I used to go out running and was able to block out the cramps until I keeled over one day aged twenty five. Took another three years of denial before i went to see my GP.

Similarly, some people felt either too proud or too embarrassed to seek medical advice:

> I am a relatively private person when it comes to medical problems so I didn't really say to anyone about it.

For many forum users, however, delays in diagnosis were affected by delays in having their symptoms recognised or taken seriously by medical professionals. One member, for example, did not have his back pain symptoms taken seriously by his doctor due to his age:

> I was told by my family GP at the time when I first started showing signs 'you are too young a man to be having a bad back'.

Another member had trouble convincing medical professionals of the physical rather than psychological nature of her tiredness symptoms:

> It took me six years and many referrals to psychiatrists before I found a neurologist who would believe me and test me.

The process leading to diagnosis was variable for members of the group. Experiences differed with regard to age at diagnosis and reasons for testing (e.g., showing symptoms, due to another diagnosis in family, family planning, etc.). What was clear was that members often experienced a number of delays in the testing process itself:

> Endless white coats, long corridors, meticulous tests……revealed that I had a form of [disease type].

Some members were diagnosed multiple times using different tests. For some forum users, this meant that they went through several diagnosis attempts until genetic testing finally confirmed their diagnosis:

> I have [disease type] and was sort of diagnosed back in the early [decade], almost diagnosed in the late [decade] and confirmed by genetics test in [year] (lol it took a while).

Others reported being misdiagnosed with another condition and consequently experiencing changing diagnoses over time. Sometimes members were diagnosed with an illness which had a similar symptom profile:

> They initially diagnosed me with [disease type] as the symptoms are very similar.

Even for some people who had received a diagnosis, their diagnosis changed again upon availability of new testing procedures, such as genetic testing due to family planning:

> I was diagnosed with [disease type] at the age of [age], but you may be interested to know that after a second biopsy which was taken for my daughters benefit (possibly starting a family) I was then diagnosed with[different disease type].

Many forum users felt then that diagnosis was "more of a process of elimination, than a narrowing down of the field" as they were tested for multiple disorders, and were diagnosed by doctors ruling out other types

of conditions. Waiting for appointments with neurologists added to members' wait for a diagnosis:

> I haven't got a date to see a neurologist yet.

While some members eventually received a diagnosis after other conditions were tested for, others never received a conclusive diagnosis. This prompted one member to decide to stop searching for a diagnosis, after being misdiagnosed several times:

> I had given up trying to get a diagnosis and accepted that I have a neuromuscular condition.

5.3.3 Sharing negative emotional reactions to diagnosis

Forum users discussed many different emotions in relation to their diagnosis experience. A common feeling among members was a sense of post-diagnosis isolation. The parent quoted below discusses his experience of a lack of support after his children's diagnoses:

> We were told last January that they both suffered from [disease type]. It left my wife and I feeling empty. There is seemingly very little support.

This lack of support was also reported by adult NMD sufferers in relation to dealing with the outcomes of their diagnosis. One member notes how he had received:

> (......) no offer of support to come to terms with the progressive illness and that I have a fifty-fifty chance of passing the illness onto any future children.

Many members noted the sense of shock they experienced at diagnosis:

> I'm in a bit of a 'shell shocked' state about this still and I'm struggling to not dwell on it.

A common response that members had to this shock was to struggle with feelings of uncertainty about what to think about their diagnosis or how they should proceed:

> Just diagnosed with [disease type]. Not really sure what to think or do.

These feelings of uncertainty caused fear and anxiety for some members. For example, one member expressed concerns about life expectancy.

Apart from shock, members also expressed feelings of loss or sadness related to the diagnosis:

> I'm a carrier of [disease type] and have 2 boys who are affected aged [age] and [age]. Struggling to come to terms with it all - it's still very raw.

5.3.4 Sharing relief at eventual diagnosis

The positive aspect of diagnosis which some members mentioned was the relief that they felt when they received a diagnosis, especially if they were waiting for a long time for this. Their diagnosis often came after receiving a referral to a specialist who had more knowledge about their condition:

> I now have a great neurologist who believed me and did the appropriate tests.

Achieving this recognition of their symptoms, and getting the appropriate tests done, was a source of relief to many members after such a slow diagnostic process:

> In a strange way it was a relief to finally have a proper diagnosis.

5.4 Sharing diagnosis support

As there was variation in members' time since diagnosis, many existing members were able to offer support to those currently undergoing diagnosis or those who had recently received a diagnosis. Members often drew on their own experience of diagnosis to reassure and validate others' experiences. A further way in which existing members supported those with new diagnoses or those undergoing diagnosis was to signpost them to appropriate information and to note the availability of support for them at this time.

5.4.1 Validating members' experiences

One of the ways in which the online community helped others was by validating their experiences of diagnosis by noting inherent commonalities in diagnosis experiences. This validation was also often apparent when members noted similar experiences of delayed diagnosis:

> I think you'll find that other members will relate to you story of how long it took to get diagnosed as many have experienced this too.

Similarly, members also noted the common experiences of misdiagnosis:

> Your story of incorrect diagnosis is, sadly, all too familiar.

5.4.2 Validating members' emotions

As well as validating experiences of the diagnosis process itself, members also offered support to each other by reflecting on each other's feelings about diagnosis. This included providing assurance to members that their feelings around diagnosis were normal. Members assured others that it was normal to feel overwhelmed or daunted by the information provided at this time:

> It can be very daunting when first diagnosed there's so much information to take in. Even now I find it can still go over my head!

Forum users also assured others that it was normal to question the impact of the diagnosis they had received:

> It is a natural reaction to feel unsure about what it might mean.

Members also reassured those with new diagnoses that everyone has different ways of coping at this time and that their own ways of trying to cope were probably quite normal:

> It is only natural you will have 101 questions, queries and concerns buzzing about you.

Finally, members often validated feelings of frustration with trying to get a diagnosis, and relief when a diagnosis was finally received. Members demonstrated that they too had experienced or understood these feelings:

> I can understand the relief you must feel (and I am sure many others here do as well).

5.4.3 Comforting and supporting members

Forum users provided words of comfort and reassurance to members who were going through the diagnosis process. This support varied, but most often included the expressions of sympathy or sadness at member diagnoses:

> I'm sad to hear about your sons' diagnoses, I know it's very upsetting when you find out that one's children are affected.

> Best wishes to you and your family at this difficult time.

Forum users also offered support to each other by suggesting strategies for coping with and accepting the diagnosis. Newly diagnosed members were encouraged to take time to get used to the diagnosis:

> I can imagine it is all rather daunting getting heads round what is happening, take your time.

Members also encouraged others not to dwell too much on the diagnosis. For example, one participant encouraged another not to let the diagnosis label affect their outlook:

> Just make the best of what you've got. Forget the name tag and don't let it get down and life goes on as you are still you..!

Furthermore, members drew on their own personal experience to reassure others of the benefits of getting a proper diagnosis. They encouraged members not to dwell on the negative aspects of the diagnosis, but to think in terms of the positives of gaining access to better medical and social care services support. One member, for example, reassured another about the potential positives of getting her husband's muscle biopsy results, as she had expressed her fears about it. The participant explained the benefits she received after having her biopsy done:

> In my case it ended years of not knowing and unlocked so much help that I look back on it with pleasure……..Within two days CS had visited my home and assessed the situation and arranged for specialists to help me, falls Prevention Service, two different sets of O.T.'s, speech and language therapists, dieticians, physiotherapists.

A further way in which members offered support to those going through or at the end of the diagnosis process was to note the types of support available to help them deal with the diagnosis and the condition. Members encouraged newly diagnosed members not to feel isolated by their diagnosis:

> Please do not feel you are alone with this condition.

5.4.4 Signposting to support and information sources

Members encouraged others to seek out support to help deal with their condition. This included reminders of the potential support they could gain from forum users:

> There are a few forum members on here with [disease type] and once you have had time to absorb what you have been told you will find that there are people, resources and support to help you manage and adapt to your condition.

Similarly, members sometimes suggested the potential benefits of seeking support outside the forum from a condition-specific support group:

> You could try dropping this group an email……they will be in a better position to offer advice.

Apart from providing assurances regarding the availability of support within and outside the forum, members also tried to help others by signposting them to sources of information on their condition:

> As a recently diagnosed person have you seen the help page on the main site? [web address]……this page also has links to other areas of information and knowledge.

In a similar way, members sometimes suggested that forum users seek a referral to a good consultant or neurologist, so that they could receive the most up-to-date information on their condition:

> Don't know where you live but go to your GP get a referral to [doctor's name] at [hospital name]. He is the best.

5.5 Discussion

The analysis presented above highlighted the salient themes relevant to the initiation of communication between members of a new OSG for people affected by NMDs. The implications of each theme will now be discussed in the context of the wider literature on OSG communication and literature related to living with NMDs. The three themes provide a considerable, novel insight into initiating factors in the development phase of an OSG, common narratives in terms of the experience of diagnosis in NMDs, and the support provided within the group in relation to affirming the diagnosis experience and providing emotional support.

The theme 'establishing common ground' covered many aspects of how conversations in the new OSG were both initiated and maintained. The processes members engage in to develop online relationships are relatively under-researched. Previous research has suggested the

importance of self-dislosure as a key processs in OSG communication (e.g., Winzelberg, 1997; Klaw et al., 2000; Tichon & Shapiro, 2003; Pfeil et al., 2010). In this case, in the newly developing group, personal disclosure was an important part of initiating conversation. It was through disclosure that members were also able to note similarities with other members and commonalities in experiences. Noting similarities between member experiences and making connections between these experiences have previously been found to help maintain solidarity between OSG users (Armstrong et al., 2012). In the present analysis, it was seen that noting similarities and connections between members' experiences was equally important in establishing online communication.

Most members disclosed their relationship to NMDs in their initial posts. This finding supports previous research that suggests that disclosing your relationship to an illness on an OSG is an important legitimisation process when joining a group (Armstrong et al., 2012; Stommel & Meijman, 2011). This disclosure therefore may have helped participants to establish their identity and status on the board.

Members expressed a desire to share experiences, and to learn from others experiencing similar issues, in their initial posts. This potentially motivating factor for use of the group could be investigated further by asking participants about their motivations directly. Posts related to sharing similar past-times demonstrated that participants were also interested in sharing common interests, as well as illness experiences. This is an interesting finding as it it suggests participants may have had both informational and social motiviations for accessing the group.

In terms of the development of the group, an important component seemed to be the sharing of aspirations about how the group might progress. The members in this group particularly envisaged its development as a "powerful resource", as well as a fun and sociable group. Therefore, even from an early stage, the moderators and members initiated threads which captured this social and fun aspiration, as well as more informative aspects. The role of moderators in developing and maintaining the conversation process is under-researched and, therefore, this study has helped highlight some of the techniques and mechanisms through which moderators influence the group development experience.

The theme 'make yourself at home' highlighted the efforts made by members to welcome and support new members and to ensure that they felt comfortable taking part in the forum. This theme again highlighted the work carried out by moderators, in terms of welcoming members, encouraging people to post and providing tips and hints on how to use the forum. This work therefore suggests a key role for moderators in setting the tone of the OSG, particularly in this initial development stage. Research on moderators' experiences and motivations of managing OSGs is just beginning to emerge (e.g., van Uden-Kraan et al., 2010) and is an area that is ripe for further investigation.

The analysis presented in this chapter highlights the existing difficulties people with NMDs have in acquiring a diagnosis for their condition. Members shared their experiences of the long and often delayed diagnosis process and the related emotional impact. The sharing of personal experiences (Haker et al., 2005; Perron, 2002; Malik & Coulson, 2011; van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008) and expression of feelings (Finn, 1999) are common features of OSG communication. The discussion of personal illness experiences in OSGs is not a finding unique to this study. However, the particular narrative around delayed diagnosis and unmet support needs that members' experience around this aspect of living with NMD conditions is significant. The prominence of this delayed diagnosis narrative in the current study may be related to the rare nature of the members' NMDs. The current analysis then provides an interesting, timely snapshot of the current psychosocial needs of people affected by NMDs in relation to diagnosis, which may be useful for health professionals and support organisations who work with families affected by NMDs.

Based on their initial posts, members were at different stages in terms of the diagnosis process. Some participants were newly diagnosed, while others were undiagnosed or had long-standing diagnoses. All members were, however, able to contribute their experience to the conversations about diagnosis. The problems that members experienced in relation to diagnosis validate previous findings about the stress that families experience in getting a diagnosis of an NMD (Firth et al., 1983; Webb, 2005; Plumridge et al., 2010). Importantly, this analysis also highlighted

the positive aspects of receiving a diagnosis, in terms of feeling relieved and gaining access to health care services for members.

Previous research has demonstrated that OSG members can help each other to normalise the illness experience (e.g., Cranwell & Seymour-Smith, 2012). Demonstrating support or empathy has been found to be a key support process in OSGs (e.g., Finn, 1999; Preece, 1999a, 1999b; Haker et al., 2005; Perron, 2002; Malik & Coulson, 2011). In the current analysis, the aspect of the illness experience that members validated was the diagnosis experience. Participants demonstrated empathy with newly diagnosed members, based on their own previous experience. The use of personal disclosure in terms of describing diagnosis experiences and communicating the possibility of support is consistent with research which shows that disclosure can be used to both seek support and demonstrate that coping is possible (Tichon & Shapiro, 2003).

As well as validating emotions and experiences, members offered words of comfort and reassurance to members who were experiencing emotional difficulties related to their diagnosis. Members also offered suggestions as to where participants could access support or information. This is consistent with previous research, which suggests that OSG members offer information, emotional support, personal experiences, and recommendations (Armstrong et al., 2012; Chen, 2012; Cunningham et al., 2008; Greer, 2000; Springer et al., 2011). Encouraging members to stay positive about their diagnosis is reflective of research that suggests that OSG members promote a positive attitude in relation to coping (Attard & Coulson, 2012; Cunningham et al., 2008).

This analysis provided a novel insight into a number of key processes in the initiation and maintenance of initial conversations in an NMD OSG. A key salient narrative for NMD sufferers and family members around the difficulties experienced relating to achieving a diagnosis, and both the positive and negative emotional impacts of this process, was identified. The supportive potential of the group was also demonstrated, even through these early discussions, with regard to validating diagnosis experiences and exchanging support in relation to dealing with this aspect of the condition.

Chapter 6: Message Posting Analysis
An Understanding Audience

6.1 Introduction

This chapter of the message posting analysis presents themes that were incorporated under the over-arching theme 'an understanding audience'. These themes relate to how OSG members used the message board to deal with issues related to symptoms and coping with NMDs. The first theme, 'collective symptom interpretation', describes how members shared symptoms, helped one another to interpret symptoms, shared learned knowledge about symptoms and encouraged one another to seek advice on symptoms from medical professionals.

'Emotional reactions to progressive symptoms' describes the range of emotions expressed in relation to dealing with progressively debilitating symptoms. The third theme discussed in this chapter, which is entitled 'supporting one another with condition management', describes how forum users provided mutual support for one another with regards to dealing with NMD symptoms and their consequences.

6.2 Collective symptom interpretation

The discussion board frequently featured descriptions of symptoms and the impact of these symptoms on the daily lives of users. Participants also sought advice from others about the normality of symptoms and the potential causes of symptoms. In response, other forum users shared personal experiences and knowledge relating to symptoms including commonalities in illness experiences. A recurring message to those who were seeking information on a symptom was to obtain further medical advice on any symptoms that were concerning them rather than relying on the discussion board for answers.

6.2.1 Sharing symptoms

A common feature of introductory messages on the board was detailed symptom descriptions, which often occurred when forum users described their diagnosis. Specific threads were also started related to symptoms which members were currently experiencing. A variety of symptoms were described. These symptoms varied amongst participants and included declining muscle strength and/or mobility, experiencing falls/accidents, problems sleeping, heart problems, fatigue, pain, muscle stiffness, seizures/paralysis, stomach problems, dizziness/balance problems, spinal curvature, dislocated hips, breathlessness, swallowing problems, and declining sexual functioning. An example of a detailed description of symptoms reads as follows:

> My shoulder blades stick out so much that even the most hardened redbull drinker would be jealous. I can now only raise my arms about 45 to 50 degrees in front of me and about the same to the side. I can just about pick up a coffee mug, but when drinking I have to support my arm with the other hand.......I have constant joint ache in shoulders, elbows and knees. I have always had the odd twinge but never this bad. My upper back muscles, what's left of them, constantly burn as do my neck muscles and biceps. I am at the beginnings of getting foot drop. I have started to trip up over nothing and taken a few tumbles.

In addition to symptom descriptions, the impact of symptoms on daily life was presented. Symptoms often had an adverse impact on everyday activities, including social and work activities. The impact of symptoms on working life is illustrated below by a participant who retired early due to ill-health:

> I worked with the [workplace] as a [job title] until I got ill health retirement last September, and although I really miss my work ......, I knew I wasn't coping with the computer, walking stairs etc.

Similarly, the effect of symptoms on travel abilities is demonstrated in the quote below. Severity of symptoms has impacted on this participant's ability to drive and use public transport:

> My [specific condition] symptoms are severe enough to disqualify me from holding a driving licence and makes getting on and off public transport a real challenge.

One common aspect of the symptom experience described in the message postings was that of deteriorating symptoms over time. For example:

> The strength in my upper body just is not what it used to be and my lower back and legs are now weakening more so than ever.

> My sloping shoulders and "wings" were the only indication I had [specific condition] until recently. I am now [age] and it feels like in the last few months things have rapidly got out of control and taken a turn for the worse.

Members also discussed a multitude of factors which exacerbated their symptoms, such as cold weather, tiredness and fatigue, as can be observed in the following quotes:

> I too am feeling more tired, even with simple tasks. I think the cold weather contributes to this as well.

> It is so difficult to measure fatigue, it can be so individual. I know for me, the level, quality and quantity of sleep have a direct effect. Whether the day before was a busy exhaustive one.

6.2.2 "Does anyone else feel this way?"

Apart from describing their symptoms, members commonly sought feedback from other group users in terms of understanding their symptoms better. Some participants wanted to know how normal their symptoms were for people with an NMD:

> I have a weak neck too……. I lay on the sofa rather than sit, and hold or prop the head at every opportunity……. When I walk my head hangs down…….Interested to see if there is anyone with the same symptoms. Maybe I just have a weak neck?

Others wanted to know if their symptoms were typical of a specific NMD condition and appealed for information:

> I would like to find out if these symptoms are typical of [specific condition]. Your help will be much appreciated.

> My daughter is a carrier and I'm concerned also about her, as she is exhibiting cramps etc. But specifically she has always suffered from a hoarse voice……. She's visiting a speech therapist, but I'm now wondering if this hoarseness could also be symptomatic of [specific condition] Has anyone got any ideas about this?

Forum users frequently sought clarification from others about how specific symptoms manifest themselves. For example, one participant sought advice about whether her mother's fainting symptoms were examples of myotonic seizures:

> Can people give me some advice on how this happens? My mother when she got to 60 suddenly started just passing out when she got up from sitting or from bed. With her she would go out like a light but then just not realise that she had just passed out. Is this the same [as a myotonic seizure]?

Some members reported that they had previously struggled to find others who were affected by a similar condition or symptoms and so had no-one they could discuss and compare their experiences with. The following quote provides an example of this feeling of isolation in relation to dealing with symptoms and knowing what to expect with symptoms:

> I'm so scared what's going to happen. I can't lift a drink without it spilling and other things, I've been looking to see if I can find anyone like me and see what has happened to them but I can't find them……I don't know what to expect?

6.2.3 Sharing knowledge/experience of similar symptoms

Support was provided to those who had questions about interpreting symptoms from members who offered their opinions and experiences. For example, in response to the above question about fainting episodes, one forum user offered her interpretation of these symptoms:

> Does your mom pass out? By that I mean is she aware of her surroundings, able to see or as you've described have no recollection? If she is passing out that doesn't sound like a Myotonic event to me!

As in the above quotation, members often helped to tease out the problems of others, by enquiring about specific aspects of their symptom experience. Further examples of this questioning process are included below:

> Have you been for respiratory lung function test???…. the reason I ask is that I use a ventilator when I sleep but pre ventilator I had constant morning sore head, lots of nose bleeds and ended up sleeping sitting up for about a year.

> Do you get the same problems with all shoes? I tend to wear trainers/slippers much of the time or I found walking shoes from Wynsors (online for only about a tenner) are quite supportive.

In some cases, suggestions were offered as to the potential causes of symptoms experienced. In the example below, one member offers suggestions regarding another member's knee pain:

> I suspect problems with knees are a result of compensating for weaknesses elsewhere in legs and back or maybe carrying extra weight if you're not getting sufficient exercise.

Sometimes the information shared was grounded in participants' experiences of similar problems. For example, after multiple users noted similar eating and stomach problems, one member shared her understanding of the potential cause of this problem as explained by her speech and language therapist:

> She explained in great detail the complex series of muscles and sphincters that stop food going in to our own airways. She says there are similar ones at the start and end of our stomach and if they are slightly "out of synch" (myotonia will obviously do this) food stays a lot longer in the stomach which stays bloated and you do not feel hungry. Also results in food becoming overly and repeatedly digested and everything finally comes out a liquidy mush.

6.2.4 Encouraging medical advice seeking

While forum users offered support to each other in the interpretation of symptoms by sharing experiences and knowledge, they were also cautious about how others interpreted advice on the forum. It was often pointed out by those who were offering advice about symptom interpretation that they did not have medical expertise and that affected members may need to seek further medical advice:

> As for your daughter - I am not an expert with [specific condition] so cannot comment about the hoarse throat issue.

> I'm not a doctor and would urge you to discuss your concerns with a neurologist, but in a purely personal opinion I'd say it was normal for someone to experience frequent chest infections.

Similarly, members sometimes encouraged others to get a second medical opinion if they were not fully satisfied with the medical advice they had received in relation to their symptoms:

> Best thing would be to go back to your GP if your still unwell, maybe see a different GP if you're not totally happy with your normal one.

6.3 Emotional reactions to progressive symptoms

A range of emotions were discussed on the forum, relating to managing the symptoms of a progressive condition and the way in which these symptoms impact on one's daily life. Such emotions included feelings of worry and uncertainty, loss and isolation. In terms of managing their symptoms, many members reported a reluctance to rely on aids/adaptations that may help them to cope better with their symptoms. This reluctance was related to disappointment in needing to rely on such aids or adaptations. In terms of their outlook on coping with their condition and its symptoms, members reported trying to maintain a positive outlook despite the difficulties they experienced and reported valuing support from close family and friends in terms of coping.

6.3.1 Anxiety about symptoms

Feelings of worry relating to symptoms were commonplace. One cause for concern was uncertainty about the nature of symptoms that were experienced. One participant, for example, discussed his concern about the heart problems he was experiencing:

> I'm a bit concerned about my heart (which I understand is typically affected/weakened by [specific condition]). My symptoms are a feeling of being very aware of my heartbeat (particularly in bed) and slightly trembly type feelings. Another symptom is that I seem very easily surprised by noises, particularly at night. My heart occasionally aches, but it's more a feeling of the presence of my heart. I also seem to get pins and needles at night in my arms. It's all rather worrying of course, and this could be affecting how I feel.

A related concern for participants was how symptoms would progress in the future and how this progression would impact on their lives. For example, in the following excerpt, a mother's concern about whether her son would end up permanently using a wheelchair after his hip surgery is highlighted:

> The specialists say he is going to need a big operation but are concerned how well his hip will recover with him having [specific

condition] myopathy. He would be in a wheelchair for at least 3 months. I worry that the wheelchair could be more permanent.

Anxiety was also expressed in terms of understanding the mechanisms through which different types of formal support could be applied for. This included uncertainty about the assessment criteria for different disability benefits, housing support and how to access different health professionals. For example, one forum user presented her worries about her family's financial future if her husband needed to give up work due to his symptoms. Her worry was compounded by uncertainty about where to access information on benefits and entitlements:

> So now comes the help/advice I need …… does anyone know what benefits or entitlements he might be able to claim he currently gets DLA and Carers allowance but that's all ……. Any advice would be a really big help as we don't know where to start. I am looking at getting job as the children are a little bit older now so that he can give up work but making that move with no financial backup is a worry.

6.3.2 Regret at declining functional ability

A sense of regret relating to declining abilities to take part in activities was also noted in discussions on the board. Grief was felt by participants in terms of losing their independence:

> Now I am housebound unless I have someone with me and I really hate being dependent on people.

Members expressed regret regarding their decreased ability to take part in a number of particular activities. One such regret was related to the loss of the ability to work and earn a living:

> I'm a qualified [job title]…… I don't find it so easy to [do job task] these days as my balance is so bad. That makes me really sad as I used to love it so much.

> What I find frustrating and soul destroying to some extent is that the only reason I'm in this financially bleak position is because I'm disabled.

A further source of regret was related to the loss of sexual ability. This often led to sadness and frustration:

> I would dearly love to be sexually active, it's one of my greatest sources of sadness.

> The loss of sexual activity is a heavy burden when i have been used to a fairly healthy sex life whilst married and of course before [specific condition] took hold. Maybe some will disagree with me here but I figure that you don't miss what you have never had but to suddenly be cut off is frustrating in the extreme.

Other forum users expressed frustration at not being able to take part in social activities such as going out or going to the cinema:

> Really want to see the second film but, can't cope in the cinema, get out of my seat or walk up or down in the dark.

> I hate this. I can't go out to parties because I can't hold a cup or wear heels.

For many members, this loss of activity meant that their social life was more limited than they would have liked, leading to feelings of isolation:

> Worst aspect of the condition? The feeling of isolation I think gets to me most.

6.3.3 Feeling unsupported in the medical management of symptoms

As well as expressing regret at the loneliness experienced due to declining social activities, a sense of isolation in terms of managing the symptoms of their condition was also reported. Some participants noted how they received little medical support due to poor knowledge and experience of NMDs by medical staff. One member discussed how she found this lack of support from her neurologist difficult to come to terms with:

> I see a neurologist at the local hospital once a year.....however he admits himself there is very little he can do for me and he doesn't even have any other patients with MD so it's all a bit of a farce.

While the lack of medical treatment available for their conditions was acknowledged by forum users, they still expected medical help in managing their symptoms and sometimes found this lack of help frustrating. One member, for example, quotes her response to a consultant who said he could not help her:

> I don't ask the impossible but I do expect a modicum of medical management.

6.3.4 Reluctance to use aids/adaptations

Due to the progressive nature of their conditions, conversations often involved discussions about aids and adaptations that members were using or considering using to help them manage daily tasks. These included crutches, manual or powered wheelchairs, car and home adaptations, etc. Many members expressed their wish to avoid depending on any aids or adaptations and to stay as independent as possible, for as long as possible. For example, in the quote below, the forum user discussed his preference to delay using a wheelchair, so as to attempt to delay any further loss of physical mobility:

> I'd rather put off wheelchairs for as long as possible and keep as active as possible to try and maintain the mobility I've got.

This seemed to be a point of view that was shared by many others, in terms of a determination to continue to persevere with life without using aids or adaptations:

> I understand all sufferers pov [point of view] that we want to struggle on and persevere with how 'normies' do everything rather than capitulate and get used to an aid, adaption or wheelchair.

While this determination not to use adaptations or aids was often motivated by trying to maintain independence, this reluctance was also influenced by concerns about other people's perceptions of these devices. One member, for example, describes his embarrassment at the idea of using his crutches:

> I too have [specific condition] but as of late am unable to go outside without 2 elbow crutches, that has only been the case since last year! I was slowly losing confidence and falling more, still can't bear to be seen with them but that's life.

Similar concerns were voiced about deciding to use other aids or adaptations. For example, one member described her reluctant application for a disabled parking badge (known as a 'Blue Badge') and an adapted car on the Motability scheme as she felt it impacted on her pride:

> With my muscle disease seemingly catching up with me I did opt for a Blue Badge and Motability. My pride took a bashing but it was that or me (literally).

6.3.5 Maintaining a positive outlook

Although forum users often discussed negative aspects of their symptoms, they also expressed a desire to maintain a positive outlook on dealing with their condition. Some noted their deliberate attempts to remain positive about their condition in order to help themselves to cope better:

> A positive mental attitude is the best way to cope with MD, so my mottos is to 'Keep Smiling' whatever life throws at you.

Members also tried not to let negative feelings, such as a sense of isolation, get them down:

> I can identify with the isolation, although like yourself, I try not to let it affect me.

Different personal perspectives were discussed in terms of dealing with any challenges related to their condition. Some advocated taking a day-by-day approach to the management of symptoms, while others opted to take a prepared approach to anticipating problems related to their condition:

> I feel the best rule for me is to ignore things until they really need looked at, one day at a time.

> My condition is getting worse and it now means the small adaptions I once made are becoming huge adaptions that I'm not always ready to make! I'm getting there though and trying to face it all head on.

Another way in which forum users demonstrated a positive outlook was to note how lucky they felt to have less severe symptoms than others who have similar conditions. This was noted in the following quotes in relation to mobility level:

> It seems like [specific condition] covers a broad spectrum and I am probably quite lucky like you and your brother to be still mobile at [age], even if a little wobbly these days.

A positive outlook on one's symptoms was also evident in the frequent use of humour when describing specific issues. For example, the following member joked about the number of falls he had taken recently and the unfortunate circumstances in which they had occurred:

> I have started to trip up over nothing and taken a few tumbles. These tumbles always seem to happen when I am in a crowded place or walking past a nice young lady or when the ground is hard. Now why is that? It is never at home on the nice soft carpet in front of the cat!

6.3.6 Valuing support from close friends and family

While a common theme in members' discussions was a decline in social participation, the helpfulness of their family and close friends in supporting them through their condition was often noted:

> I've got a great, supportive family, my circle of friends has got a bit smaller as I'm not able to get out and about as much but the ones I have are amazing.

This experience was echoed by others who noted, for example, that friendship was a "quality rather than a quantity thing".

6.4 Supporting one another with condition management

Apart from helping each other interpret symptoms, as in section 6.2, forum users provided support to help each other cope with their condition in several ways. These processes included the sharing of information, the provision of emotional support and reassurance, and encouragement to take a pro-active approach towards fighting for access to any services, adaptations or aids needed to help manage the condition.

6.4.1 Sharing information

One way in which support was offered was through the provision of information or by directing others to information sources that were related to ways in which members could help themselves to cope with their symptoms. Forum users shared experiences or tips based on how they personally managed their condition. This included information about such topics as physiotherapy, chiropody, massage, healthy eating, exercise, using special pillows, footwear, ventilators, etc.:

> I find massages help my circulation when I've had one.

> I have just "upgraded" to using 2 sticks and even just got hold of some Wheel away winter spikes for the crutches, will hopefully prevent any falls on the icy pavements this year.

Information was also provided on services or information resources to help people cope with their condition. For example, the quote below shows how people who had issues around securing disability benefits

were directed to information sources within the forum. The underlined text shows links to other threads on the forum.

> We have a thread on here about *making sure you're getting all the benefits you're owed.* Carers.org also have a section on their website with information about money and benefits that carers are entitled to. Hope this helps as a start.

6.4.2 Validating feelings regarding symptoms

Forum users provided support to each other by validating each other's experiences and feelings related to symptoms. As noted in section 6.2.3, members often noted similar symptom experiences:

> Our symptoms are very much the same apart from the feet.

> I too am experiencing "weird" stomach symptoms.

They also helped normalise symptom experiences that forum users had expressed uncertainty about. For example, the member in the quoted excerpt below discussed the normality of back pain for those with a particular type of NMD due to curvature of the spine that is typical of the condition:

> I get backache in my lower back quite a lot..I think because of the curvature on my spine which is common with our condition so I think this is quite normal.

In response to this sharing of similar experiences, a feeling of reassurance was often noted by those who felt uncertain about symptoms. Specifically, they felt relieved not to be the only one experiencing these symptoms and related difficulties:

> Nice to know I'm not the only one with the dribble problem.

> I'm glad that I started this thread, first because I'm interested in those Yaktraks and second because it's reassuring to know that I'm not the only one who has problems in this weather!

Due to the variability in the types of conditions which members were affected by, and different experiences in terms of disease progression, forum users also reassured each other that not all symptoms would be experienced by everyone in the same way:

> As my condition as with other forms of [condition type] can be so variable between individuals it is difficult to compare notes.

Support was also offered through validating or normalising negative emotional reactions to symptoms. For example, one forum user reassured a younger member that it is ok to have fears for their future and that both she and others on the forum have experienced similar feelings:

> It is totally natural to feel scared of an unknown future, I was at your age and yes having medical personnel tell you they can do little to help does not do much to bolster the hope you have. Have no fear, all of us here have experienced the same as you at some point.

More specifically, forum users also noted similar feelings in relation to feeling upset about having to use aids or adaptations that they might need to help them cope with their condition:

> I felt the same when I finally admitted I needed a blue badge for my car. And then I got a lovely new car on motability……try to remain positive.

6.4.3 Reassuring members of available mutual support

In a similar way as when new members initially joined the group, users of the group continued to offer support to others and assurance of the availability of informational and emotional support from fellow members. For example, one member who had asked about how others deal with pain was told:

> Keep checking back to see what others have to share.

Similarly, members reassured one another of the availability of emotional support on the forum. Forum users repeatedly reminded others that they were not alone in their experiences of NMDs and that support was available on the forum:

> Most of all (member's name) – you are not alone.

> You can drop me a line any time if you feel the need to talk

> You and your son have my best wishes as that is all I can offer through the internet.

6.4.4 Encouraging a positive outlook

As well as describing their own attempts to maintain a positive outlook in terms of coping with their condition, members also encouraged others to adopt a positive outlook. For example, in the excerpts below, OSG users were encouraged by others not to let their experiences of their condition affect their mood:

> Just don't let it get you down and keep "your chin up" :).

> Maybe we can all try and focus on the upside of things rather than the negative. I do feel that for every closed door another one opens.

A common issue which members encouraged others to be positive about was the use of aids or adaptations to help manage their condition. Forum users also reassured others of the value of using these devices by describing their personal experiences of the benefits of using such supports. In the following excerpt, a member provided reassurance to a user who expressed concerns about starting to use a ventilator, and described the personal benefits they had derived from using this machine:

> It can take a while to get used to using it but the pros outweigh the cons in my opinion. I had more energy and less headaches in the morning.

Members were happy to meet others who had similar experiences of using aids or adaptations:

> It's nice to hear from someone who has experience of wearing a splint too and knows they can be painful.

6.4.5 Encouraging a pro-active attitude to support seeking

A commonly shared experience was difficulties in securing suitable adaptations and aids to help manage symptoms. As an example, one member struggled to find council housing with a suitable accessible shower:

> The house had a bath and due to my disability require a level access shower. There's no way I would have managed to get in and out of a bath, I tried everything to have [details removed] city council fit it (inclusive of self-referring to OT) with the required level access shower to no avail so had to refuse the allocation, It took OT 6 weeks to get round to writing to me offering me a meetings with regards my various complaints.

Drawing on their own personal experiences, members encouraged others to fight for any adaptations or aids that they currently needed. In response to the member's story above, one member noted her similar experience of struggling to get a suitable bathroom in her council accommodation:

> Sadly your experience with your local council is not unique. I had to survive a couple of years of strip washing before my bathroom was converted.

She then encouraged the other member to be persistent to get their needs met:

> Keep on at your OT, local council and hospital peeps, hopefully someone will get hosed off being nagged at that you'll get success.

In a similar way, members encouraged others to fight for any other services that they needed. Below is an excerpt in which a forum user is encouraged to fight for medical support in managing their condition:

> I can appreciate your frustration and wanting to just 'manage yourself', but keep chipping away at your GP, maybe get a referral to a neuro consult. If only for assistance in monitoring and managing long term.

6.5 Discussion

In summary, this analysis has demonstrated that members used the discussion board in a number of ways in relation to sharing their experience of living with an NMD. Participants used the board to describe and find out more about symptoms. They also shared their emotional reactions to symptoms and the impact of their condition on their daily lives. Members then offered one another emotional support in terms of coping on a daily basis.

Consistent with previous OSG research, members used the board to discuss symptoms and coping with illness (Armstrong et al., 2012; Barney et al., 2011; Haker et al., 2005; Springer et al., 2011). Similarly, in line with previous research, forum users offered one another informational support, emotional support, personal experiences and recommendations in terms of managing symptoms (Armstrong et al., 2012; Chen, 2012; Cunningham et al., 2008; Springer et al., 2011).

As found by Tichon and Shapiro (2003), disclosing information about symptoms was used both in the elicitation of advice, and provision of support. Participants disclosed information about their symptoms, the impact of their condition on their daily lives and their emotional reaction

to these symptoms. Following disclosure of their disease experience, members often sought advice about the normality of the symptoms they were experiencing and other members shared their experiences in return when offering support. Participant descriptions of their disease experience also included disclosure of sensitive aspects, such as the impact on sexual function. This supports previous studies which have shown that members use OSGs to discuss intimate or sensitive issues (Attard & Coulson, 2012; Broom, 2005a, 2005b; Gooden & Winefield, 2007; Malik & Coulson, 2008; Sullivan, 2003; Springer et al., 2011).

As there is a lack of medical treatment for many NMDs, treatment decision discussions were not as prominent as they may be in other groups. This could be due to the progressive, non-curable nature of many of the NMDs which members were affected by. In fact, when medical management of their condition was discussed, this related to a sense of isolation in terms of being left to cope on their own with symptoms by medical professionals or feeling that medical professionals did not understand their condition enough to be able to provide appropriate support. The isolating effect of progressive symptoms has previously been noted in the NMD literature (Boström & Ahsltröm, 2004; Krause-Bachand & Koopman, 2008).

A further negative reaction to symptoms that forum users described was anxiety relating to symptoms and symptom progression. Loss of control related to progressive symptoms and feelings of fear and uncertainty have been previously identified in research on the experience of living with NMDs (Boström & Ahlström, 2005; Krause-Bachand & Koopman, 2008). Participants described the impact of their condition on a variety of life activities. Previous research has also noted the impact of NMDs on social participation (Grootenhuis et al., 2007) and social participation levels have been found to decline over time (Boström et al., 2005). As highlighted in this analysis, those affected by NMDs experience particular problems in relation to mobility, housing, employment (Gagnon et al., 2008) and leisure activities (Gagnon et al., 2008; Vuillerot et al., 2010).

The feeling of regret relating to declining activities, which was highlighted in this analysis, has been identified previously (Boström & Ahlström, 2004). The reluctance expressed by members on the forum in starting to use aids or adaptations to help manage their condition has also been

identified in the NMD literature. For example, Webb (2005) found that NMD sufferers and carers may have reservations about using ventilators as moving to using such breathing aids may exemplify symptom progression. In this analysis, however, the effects of feelings of pride and of other people's reactions to aids or adaptations were also important in the decision making process to use such supports.

These findings, regarding the emotional reactions and difficulties related to progressive symptoms, highlight an important area for potential psychological support interventions for this population. Participants found declining functional ability particularly difficult to deal with. These difficulties were amplified by a perceived lack of understanding of their condition by health professionals and a lack of medical management of their condition. The absence of curative treatments for NMDs may mean that OSG users are particularly isolated if they do not receive on-going medical support.

Members noted their intention to maintain a positive outlook on coping with their condition, which has been previously identified as a key component of coping for those with NMDs (Lamb & Peden, 2008). They sometimes used comparisons with others to note how lucky they felt that their symptoms were not as severe. This use of comparison has been identified as a way in which people with NMDs contextualise their illness experience (Krause-Bachand & Koopman, 2008; Mah et al., 2008; Nätterlund et al., 2001). Forum members discussed the importance of close friendships and support from family. Maintaining strong social relationships has been previously documented as an important coping resource for people with NMDs (Lamb & Peden, 2008). It is difficult, however, to assess through the current analysis whether the use of the OSG had any impact on users' ability to cope with their condition. This type of information can only be garnered by consulting OSG users directly.

The current analysis confirms the importance of both informational and emotional support exchange in OSG communication (e.g., Coulson & Greenwood, 2012; Coulson et al., 2007; Coursaris & Liu, 2009; Mo & Coulson, 2008). An important function of the group, as identified in other OSG research (e.g., Attard & Coulson, 2012), was the provision of information or advice about managing one's condition. In particular on

this forum, the exchange of information on interpreting symptoms was prominent. While members offered information and advice on interpreting symptoms, they also noted the limits of their advice as lay people and suggested that members seek further medical advice when needed. Therefore, forum users were cautious about their own expertise. A further area in which participants provided informational support was in the sharing of hints and tips for coping with the condition and directing others towards further support or information sources in relation to a range of different topics, from medical management to securing disability or carer benefits.

In terms of emotional support offered in relation to symptoms, members provided support to one another in a variety of ways. In line with previous research on self-help processes in OSGs, members commonly shared support and empathy and shared their own personal experiences in order to support others (Haker et al., 2005; Perron, 2002; Malik & Coulson, 2011; van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008). Members demonstrated empathy by noting their understanding of participants' symptom experiences and feelings. Previous research has suggested that members of OSGs can help normalise each others' illness experiences (Cranwell & Seymour-Smith, 2012).

What is interesting about the information seeking and sharing regarding symptom management in this particular OSG context is that participants often felt isolated in the interpretation of their symptoms, due to their lack of contact with others with similar conditions. Thus, the OSG provided an outlet for questioning the 'normality' of their widely varying symptoms and an opportunity to help interpret their symptom experiences in the context of other NMD sufferers. Participants often normalised symptom experiences for one another by noting similar symptom experiences and feelings. Members also normalised symptoms which were not commonly experienced by noting the variable symptoms experienced by people with a variety of NMDs. Thus, forum users accommodated members who had both more readily identifiable and less common symptoms. This is an important and potentially unique feature of OSG use for this population as members would not readily have access to such a wide variety of people who experience such varied symptoms.

Discussion board users provided particular emotional support in terms of encouraging others to maintain a positive outlook. This is a support mechanism that has been noted previously in OSG research (Attard & Coulson, 2012; Cunningham et al., 2008). Participants varied in terms of preferences for taking a day-to-day approach to coping, or taking a planned approach to anticipating the next steps in their condition. A preference for taking a day-to-day approach to coping has been previously noted in interview studies with people with NMDs (Gibson et al., 2009; Nätterlund et al., 2001). Members generally encouraged each other to take a positive approach to living with an NMD, but also specifically encouraged each other to be resilient in terms of fighting for any services or adaptations they needed to better cope with their condition. Members also offered encouragement to others to be accepting of any aids or adaptations they needed, as a reluctance to rely on these was often mentioned.

The analysis supported previous research on the information and social support functions of OSGs. The themes also reflected a number of key issues relevant to living with an NMD that have been previously identified in the literature. The analysis reveals a number of potentially unmet needs which members may have. In particular, members sought support in relation to interpreting their symptoms, dealing with the emotional and practical impact of progressive conditions and the isolation felt when trying to access medical support and other support services.

Chapter 7: Message Posting Analysis
Recognition and Awareness

7.1 Introduction

In this final message posting analysis chapter, the over-arching theme 'recognition and awareness' is presented. This theme describes how the message board was used by members to discuss their illness experiences, within the broader societal and political climate. The rare nature of many of the NMDs that members were affected by contributes significantly to the narrative described here.

The first theme, 'sharing difficulties with public perception of disability', charts members experiences of difficulties relating to gaining understanding of their condition from medical professionals and the public, as well as difficulties members experienced related to current government and media portrayals of the role of disabled people in society. The second theme, 'fostering discussion on political, societal and healthcare issues', describes how the forum was used to share information on news items related to political changes that may be of relevance to members and those with disabilities generally. The final theme, 'raising awareness', describes members' bids to counter a lack of knowledge and perceived misperceptions about their illness through a number of mechanisms.

7.2 Sharing difficulties regarding NMD recognition

Members often discussed difficulties they experienced in terms of dealing with other people's lack of understanding of their particular condition or of the needs of disabled people generally. These difficulties were evident in descriptions of encounters with health and social work professionals and the general public. Members also felt let down by how the government and media were portraying disabled people, as they felt this type of portrayal of disabled people would lead to further misunderstanding about disability and the alienation of disabled people.

7.2.1 Facing poor professional understanding

As mentioned earlier in section 5.3 ('sharing diagnosis experiences'), members often faced problems in gaining understanding about their symptoms and their condition from health professionals:

> [Member's name] made the point, a lot of our conditions are rare, unique and different. What is so obvious is that even the best specialists do not completely understand them.

This was often due to the rare nature of their conditions and the fact that some doctors and nurses lacked specific expertise. Members reported encounters with health professionals in which these professionals demonstrated a lack of understanding of these types of conditions. One doctor wrongly suggested to a member that she couldn't possibly have muscular dystrophy as it is a condition specific to boys:

> And do you know what one of the doctors told me 'You can't have muscular dystrophy, only boys get muscular dystrophy.

This lack of understanding presented problems for members, not only in terms of getting an initial diagnosis but also in terms of subsequent treatment:

> My poor GP has very little knowledge of my case and it was only with my back up letters from the neurologist that allowed him to give me tablets for headaches.

Members often reported having to explain their condition repeatedly to new health professionals and described the emotional impact of professionals demonstrating a lack of understanding of their condition. The participant quoted below described her feeling of being under attack when asked about returning to work by a nurse who did not seem to understand how the disorder affected her:

> Had to go for a review today of a foot problem at the Wound Unit, greeted by the Nurse who does the dressings with the statement after I had applied my wheelchair brakes, 'So are you going to be one of the ones going back to work soon'? I was rather gob-smacked and felt that I was under attack.

This lack of understanding of their condition also caused difficulties in terms of dealing with social services professionals. One participant for example, reported his frustration at being recommended to apply for several jobs which were unsuitable for his condition:

> At least the Work Focus Interview Mafia are leaving me alone these days, it was a typical example of the "cream and park" system with them on the blower every other day with unsuitable jobs.

7.2.2 Contending with public misconceptions

Members also reported a number of ways in which they felt the general public also had misconceptions about their condition, which at times frustrated members or made them feel excluded. Members reported a number of situations, for example, where they felt excluded from conversations, due to perceived differences between disabled people and able-bodied people. One particularly common example of this was in conversations about sex and relationships. Members often felt either cut-out from such conversations or perceived that others were embarrassed to discuss these issues with them:

> No one thinks of people with disabilities as sexual beings. We're not seen as being able to be in a relationship, let alone have sex!

Members also reported difficulties in relation to people's reactions to their symptoms, which displayed a lack of public understanding of their symptoms. For example, one member asked if anyone else had experience of people thinking they were drunk if they struggled with mobility in public:

> Do others find that if you fall over or struggling in public that you get the feeling that everyone whose staring at you is giving you the same look given to a drunk?!

Another member noted agreement when she discussed the unpleasant feeling when people mistook her for being drunk when she had a paralysis attack:

> I once had a paralysis attack in the loos in the pub and everyone just laughed and thought I was really drunk! Its a horrible feeling, I guess people just don't think that there might be another reason for your strange behaviour!

Some members felt that these issues with the public misinterpreting symptoms may be a phenomenon that applied mainly to those without overt signs of disability, such as those not using a wheelchair:

> I'm guessing this is more of an issue for those of us not as visibly disabled as those whom are wheelchair-bound though. Some of it's

probably just in my head but I do think there is a bit of a "you're not in a wheelchair so you're not disabled" thing going on.

7.2.3 Feeling misrepresented by government and media

At the time when the message posting analysis was carried out, welfare reforms had been announced by the Government. Some members felt that the manner in which the reforms were discussed by Government and the media misrepresented disabled people. Feelings of frustration and disappointment about the messages that the Government was sending to the general public about disabled people were noted. One member, for example, discusses how she felt that members of the House of Commons showed disrespect to disabled people by cheering the announcement of cuts to disability benefits. She felt that the encouragement for the welfare cuts for disabled people was reminiscent of times when disabled people were not valued by society:

> Is it just me or were people horrified at the moment the welfare reforms were announced in the Commons? One would have thought it was a very sombre moment announcing measures that would cause hardship to many thousands of disabled people. Instead Mr Osborne was smiling and receiving rabid cheering from the benches behind him……I say it shows no respect for the people affected and harps back to a time when people were looked down on if they were disabled.

As well as feeling let down by the Government's attitude towards disabled people, members felt that current media coverage of changes to the benefit system was disrespectful. One member felt that the tabloid media were "portraying us as lazy scroungers sponging off the state". Another member discussed how she thought the media were influencing the general public in terms of the necessity for welfare cuts. She thought the increased coverage and attention being placed on catching those who defraud the benefit system forced the general public to agree with the need for such cuts to welfare:

> Suddenly there are all these documentaries on benefit cheats. The average person sees this and blindly agrees with the right wing media that Welfare must bear the brunt of the cuts.

Due to this perception that disabled people were being negatively portrayed by the media, especially in terms of their dependence on welfare, some members noted the feelings of uncertainty and vulnerability that this kind of coverage provoked in them:

> Disabled people are being mercilessly slated by certain Right Wing sections of the media and I know from a different site how vulnerable and scared many of us are feeling lately.

7.3 Fostering discussion on political, societal and healthcare issues

The discussion board often became a forum for discussion about key political, societal and healthcare issues that were arising at the time messages were posted. Members often engaged in detailed discussions about their own concerns about how these issues would impact on their lives.

7.3.1 "Have you heard?"

Members of the discussion board, in particular volunteers or staff of the charity, often posted news items related to political, social or healthcare issues for the attention of discussion board members. This included news stories and research news items, as well as letters from the charity on government or media reports which may have been of relevance to those affected by NMDs. For example, one forum moderator posted the results of a carers' survey by another charity:

> Over one in three (37%) carers do not want to wake up in the morning because of dire financial circumstances and is calling on the government for greater support, reveals new research launched today (Thursday 23rd September) by The Princess Royal Trust for Carers……Really shocking findings, but sadly not surprising. It's about time the government supported carers properly.

The presentation of these news items was often then used to engender debate or discussion on these particular issues. For example, in the following quote, members were told about and given a link to a statement on the potential impact of government funding cuts on clinical research,

which may impact on research to find a cure for NMDs. The quote finishes with a question asking members to present their views:

> The [charity name] has been warning that proposed cuts to government spending on clinical research could stop much of the vital work being done to find cures for progressive and sometimes life-limiting neuromuscular conditions. [Charity director of research] _has commented on potential research funding cuts_ ahead of the Spending Review announcement next week. What are your thoughts?

7.3.2 Sharing concerns and hopes regarding political change

In response to news items posted on the discussion board and to members general discussions about changes in the health care or benefits system, members frequently discussed their concerns about potential changes. A key concern for many members was how new benefit awards would work:

> If anyone has any ideas about how people with indefinite awards will be affected I'm sure we'd all like to know.

Members also expressed concerns about how new work capability assessments would be carried out, as they were unsure of the specific processes involved:

> Yes it is worrying about reassessments, especially as the goal posts seem rather flexible and bear no correlation to what is needed to be an effective employee.

In terms of welfare reforms, members also expressed anxiety that disabled people would be targeted unfairly or disproportionately by any benefit cuts, feeling that they may become soft targets for money savings:

> I too find this worrying as without sounding hard done by the disabled seem to be being 'victimised' by government in their cuts.

> The scale of these impending cuts is massive and unprecedented. There is no scenario other than that the disabled will be disproportionately targeted. They cannot fight back and have far less "clout". Suddenly there are all these documentaries on benefit cheats. The average person sees this and blindly agrees with the right wing media that Welfare must bear the brunt of the cuts. For politicians to start talking about "lifestyle choices" is morally repugnant. I fear the disabled will be easy targets and be engulfed by a tide of political hysteria.

Members also discussed fears for how benefit cuts could impact on their quality of life if they had to manage on less money:

> These cuts worry me as my life at the moment runs smoothly, I am able to have care how I want, I'm able to go out when I like. If these proposed cuts were to go ahead I am suddenly going to find myself existing rather than living.

Concerns were also expressed about financial cuts that may impact on neuromuscular care in particular. For example, in response to a news item on potential cuts to funding for research in NMDs, one member discussed her sense of regret that research progress will be stilted by these cuts:

> That is very depressing news, I hope the cuts to funding are not too drastic as it could set us back years.

While members mainly expressed concerns about proposed changes to benefit and health care systems, there was also some hope expressed that some changes, such as increasing GP control over service commissioning, may actually improve outcomes for members:

> I am anxious about the changes ahead. I am fortunate to have a very supportive GP but until I changed surgery a few years ago this was not the case. I shudder to think the fight I would have on my hands if I still had my old GP. I am not sure that the current system works either, I have been involved in a lot of the politics of funding with my PCT and their inability to listen and understand my condition has been astounding at times. Regarding the proposed commissioning changes, I am hopeful but not yet convinced.

7.4 Raising awareness

In a reaction to problems encountered by discussion board users in gaining understanding from professionals, the government, the media and the general public about their condition, members discussed their efforts to raise awareness of their conditions. This was primarily achieved through educating others on their condition and by keeping up-to-date with campaigning. An appreciation was also shown of the value of volunteering, fundraising and charity work and in particular research to help raise the profile of NMDs.

7.4.1 Raising awareness through educating others

Members frequently discussed the need to educate others to raise awareness of their condition. Sometimes this awareness raising was done indirectly, for example, through the writing of blogs, and personal websites:

> At the time of diagnosis we were told we were one of only 12 families worldwide to be diagnosed with the dominant form of the condition, so I decided to set up a website about the condition which I have run for over 9 years.

Members also posted educational content on the discussion board that they thought may be informative or helpful in raising awareness:

> Thanks for posting that video. It's really informative and I'm going to post a link to it from the [charity website]. Don't know about anyone else but I hadn't seen or read about this condition before, so have learnt a lot today.

More often, members reported educating people as they encountered them, such as when they met health and social workers. Members encouraged each other to take expert roles in the management of their condition or their family member's condition, reminding them that they were more knowledgeable than anyone on their own experiences of the condition:

> Don't fear what un-knowledgeable medical professionals think, you are the expert on [son's name's] condition, remind them of that and remind them that unless they have strong knowledge of [condition type] they'd do well to listen and learn.

Members commended others when they took an educating role in terms of managing people's lack of understanding of their condition. For example, one member felt the need to educate a nurse about her condition after the nurse made an inappropriate comment about returning to work because of proposed benefit changes:

> Lets say by the time I left she was fully aware of a few basic facts of life regarding how these disorders can affect us.

This type of reaction was commended by others on the forum, and in this instance another member replied:

> You go girlfriend!

7.4.2 Raising awareness through campaigning

Members frequently discussed current campaigns that they could get involved in to raise awareness of their condition, or to raise awareness of issues affecting disabled people generally. For example, one member noted how he was feeling encouraged by news of a protest against Government cuts:

> But it's really encouraging to hear about the protest on 3 October. It's about time politicians started listening to the people who are going to be most severely affected by the cuts.

Members generally lent their support to, or commended, involvement in campaigning. One member noted how the recent Government cuts had a positive side, in that they encouraged a new wave of disabled rights campaigners:

> The only saving grace is that I am sure Mr Osbourne created thousands of new disabled rights campaigners at a stroke.

Similarly, members showed their support for campaigns to raise awareness of disability issues or issues relating to NMDs by taking part in campaigning. They also took part in awareness-raising meetings and conferences, and reported participating in surveys or petitions about disability-related topics:

> Signed and will be writing to M.P. on the subject.

7.4.3 Valuing volunteer and charity support in championing issues

Members also noted gratitude for the charity which hosted the discussion board in terms of working to raise awareness of issues faced by people with NMDs:

> [Charity name] is excellent at campaigning and lobbying to get our voices heard and you will find ways to get involved here on the forum at the main site.

> Things are improving and [charity name] are battling at the fore front for us

An appreciation for volunteers who work to raise the profile of NMDs was also evident on the board. The board was sometimes used to recruit and share information about volunteer opportunities, to both raise awareness of the condition and to contribute towards fundraising:

> We know there is a lot more that needs to be done and we're always very grateful for volunteers and fundraisers who can help us spread the word.

> If you're really passionate about increasing the awareness of muscle disease in your local area then you may be interested in some of our volunteering roles such as 'volunteer speaker'. This role is all about getting in to the community to spread the word about [condition type] and [charity name] Take a look at our volunteering roles at: [weblink].

The benefits of volunteering, in terms of improving the profile of NMDs, were also discussed by those who had active involvement:

> I am a member of the [name of support group] and it is so good to feel that I am doing something constructive to help improve support and services in my area - it is only when you meet other people and hear their experiences that you realise just how bad things can be in terms of quality of care.

7.4.4. Valuing research in terms of hopes for the future

A final way in which members discussed raising awareness of NMDs was through the discussion of recent research news. This news was often posted by a staff member from the charity. Members' responses were often positive about the potential for research to improve care in the future for people affected by NMDs. One member discussed how she hoped research would increase awareness, so that others did not have to experience diagnostic delays:

> Really glad to see that research is being done, it's much needed! It took me 6 years and many referrals to psychiatrists before I found a neurologist who would believe me and test me. An increased awareness will hopefully prevent others going through the misery I went through to get a diagnosis.

Others hoped that continued research would help develop treatments or cures for the conditions. For example, one affected member shared his hopes that research may progress, so that members' children may not be at such risk for passing on a condition:

> Hopefully by the time they have any children research will be that much further along by the time any affected sons (50:50 whether sons would be) it might not be as much of an issue as it is for us.

7.5 Discussion

The themes presented in this chapter described how members used the message board to discuss wider societal and political issues relating to living with NMDs. This was an unanticipated facet of the online experience. The inductive approach to this research, in contrast to previous theory-driven approaches, enabled unforeseen aspects of the online experience, such as this wider societal context, to emerge. This analysis demonstrates how wider societal and political issues can cause stress and burden on people with NMDs, in addition to any difficulties they face in dealing with medical aspects of their condition.

A primary concern for members was how their disability was perceived by others. The challenge of having their rare condition recognised extended to both encounters with professionals and with their interactions with members of the general public. Members also expressed dissatisfaction with how disabled people were being portrayed by the Government and media sources in relation to recent welfare reforms. This point is particularly relevant and topical at this moment in time.

Members used the board as a forum for the discussion of news items related to living with NMDs, such as changes to political, social and health care systems and specifically to air their personal concerns about how changes may affect their lives as people with disabilities. Members also discussed and practiced several ways of raising awareness of NMDs, so that the lives of people affected by these conditions could be enhanced.

The fact that members had unique difficulties related to the expertise of health professionals and lack of public awareness of their condition is consistent with research on the illness experiences of those with rare disorders (Schieppati et al., 2008). Managing misconceptions regarding symptoms has also been previously identified within the NMD literature (Krause-Bachand & Koopman, 2008; Sadjadi et al., 2011).

The additional problems members discussed related to the media and Government portrayal of disabled people was an unanticipated extra source of burden experienced by discussion board members. These conversations may be particularly relevant, due to the political climate of

welfare cuts within which these discussions took place. This particular discussion board was set up by a charity group which raises awareness and supports those with NMDs. Staff members and volunteers were involved in initiating and contributing news items related to political and media coverage of issues related to NMDs. It remains to be seen whether other organically grown OSGs, which are not funded or developed by charity groups, would contain the same political focus.

The concerns members expressed about changes to the healthcare and benefits systems highlights the additional burden that political change and ensuing uncertainty had over how members perceived their ability to manage their condition. Uncertainty about welfare reforms and new work capability assessments created concerns for members, in terms of whether or not they would be able to maintain their current benefits. A lack of understanding of how particular policy changes would affect those with NMDs created fear among members, as they worried about maintaining their quality of life and independence if they experienced cuts to their benefits. This uncertainty highlights the need for clear advice regarding the implications of policy changes, so as not to cause additional stress on those suffering with long-term illnesses.

Message board members used and advocated a variety of approaches to raising awareness about issues faced by those with NMDs. This may have been a particularly important theme, due to the rare conditions that members suffered from and the difficulties members had in getting others to understand their condition. One of the techniques participants used was educating others and becoming an authority on their own illness experience. Mah et al. (2008) previously found that parents of children with NMDs used this approach of becoming an expert on their child's condition, which then in turn helped mediate their stress as they could better advocate for their child's needs with health care professionals. In this case, both those with NMDs and their carers were encouraged to take on this educating role.

The campaigning that members advocated or participated in reflected participants' desires to make changes in the lives of people affected by NMDs and people with other disabilities. The encouragement of political activism has been noted in other health-related OSGs (e.g., Peterson,

2009). Collective action has been identified as one of the potentially empowering outcomes of OSG participation (e.g., van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008). In this case, collective action was realised through participation in surveys, sharing information and participating in protests, and writing letters that raised the profile of NMDs outside of the forum. The positivity demonstrated towards volunteering also links in to this promotion of collective action. Finally, in relation to raising awareness of NMDs, the promotion of information on clinical research also fed in to the hope that medical knowledge of NMD causes and treatments may develop over time, so that people with NMDs could be better supported.

In summary, the themes presented in this chapter provide an insightful overview of the societal and political aspects of living with an NMD that were discussed on the forum. Public perception of disability emerged as an important concern for members. Changing political policies, regarding welfare and healthcare reforms, concerned participants in terms of the uncertainty that such changes would bring regarding their independence and quality of life. Group members also developed a collective narrative regarding the importance of raising awareness of NMDs and contributing to change by becoming active in campaigning. This type of social and political discussion may be more prominent on this particular OSG discussion board, as the board was set up by a charity which campaigns and provides support for people with neuromuscular conditions.

7.6 Message posting analysis – overall summary

The message posting analysis presented in Chapters 5-7 revealed the emergence of three over-arching themes. These themes described how members used a new online support group for NMDs over the first five months of the group's existence: 'connecting and sharing'; 'an understanding audience' and 'recognition and awareness'.The first theme, 'connecting and sharing', gave an insight into how members integrated with the new group initially through establishing common ground and supporting each another with diagnosis experiences. Key processes involved in establishing this sense of community included: the disclosure of personal information; connecting with similar others; welcoming

members; and sharing aspirations for how the group may develop over time. Members also discussed their relationship to NMDs in their initial posts, which led to the discussion of diagnosis experiences. The central narratives members shared were diagnostic delay and mixed emotions. Members worked to support one another by validating one anothers' experiences and emotions, offering support and signposting to information resources.

The second theme, 'an understanding audience', described how members used the board to discuss and explore issues relating to their symptoms with others who might have a greater understanding of their experience. This process often began with a description of symptoms, as well as questions to other members about whether they had experienced similar symptoms. Members reacted by sharing personal knowledge and experiences of symptoms and by encouraging medical advice seeking. Participants used the board to share their emotional experiences of dealing with progressive symptoms, including anxiety about symptoms, regret related to declining functional ability and reluctance to use any aids or adaptions. The experience of feeling unsupported in terms of the medical management of symptoms and efforts to maintain a positive outlook were also reported. As in the first theme ('connecting and sharing'), where members offered support in terms of diagnosis experiences, members also provided support in terms of coping with their condition. Specifically, they did this by sharing information, validating emotions, reassuring others about available support on the board, and encouraging positivity and a pro-active approach to support seeking.

The final theme, 'recognition and awareness', described how members used the board as a platform to discuss issues relating to the recognition of their conditions. In particular, they shared their experiences of having difficulty getting their condition recognised both by professionals and members of the general public. They discussed particular concerns about the portrayal of people with disabilities such as NMDs by the Government and media sources. The board was used as a discussion forum for issues and news items regarding political, societal and healthcare issues, where members shared both concerns and hopes about how changes may affect the lives of members and their families. Members shared efforts in raising awareness of these often-rare conditions through education and campaigning. Charity and research activites were advocated by members,

as such work was perceived to champion issues for those affected by NMDs.

In summary, the message posting analysis provided a comprehensive overview of the key thematic content of the posts to a new online support group for people with NMDs over the first five months of its existence. A clear picture was built up of how members used the board and how they developed connections with one another. It was clear that the board was used to discuss experiences of NMDs in terms of medical aspects of the condition and information exchange. In addition, there was a strong social aspect to the forum, which was demonstrated by members welcoming and supporting one another with difficult experiences such as diagnosis and symptom experiences. There was also a wider social and political aspect to how members used the group. This was evident through member discussions about the difficulties in gaining recognition for NMDs and efforts to raise societal awareness.

7.7 The pursuit of a comprehensive understanding: rationale for further qualitative inquiry

The analysis of message postings presented in Chapters 5-7 provided a detailed overview of how this online support group was used by all active users in the first five months of the group. This method was particularly useful as the results of the analysis are based on all participants' contributions to the group. The analysis is based solely on participant-generated, naturally-occuring data. This allowed the analysis to be firmly grounded in participants' actual online experiences and allowed the researcher to access the experiences of all active users of the group who may not take part in traditional participatory research.

The limitation of this methodology, however, is that the researcher was not able to fully explore aspects of the online support group experience which were not directly accessible from members' message posts. Leading on from this element of the study, there are remaining questions which cannot be answered using this passive research methodology. In order to gain a more comprehensive understanding of the online support group experience, the next component of the study, described in Chapter 8, uses

a qualitative interview method to address these remaining questions. The participatory nature of the interview study will allow the researcher to examine unexplored areas of the online experience which were not accessible in the current message posting analysis component. The interviews will be particularly useful in order to gain participants' reflective accounts of their experiences. In particular, the questions which will be addressed in the interview component include those relating to members' motivations for using this online support group, factors which influence engagement with the group and any personal impact of participating in this group.

Chapter 8: Interviews

A Valued Connection

8.1 Introduction

In the previous empirical chapters (Chapters 5-7), the results of a thematic analysis of message postings to a new OSG for NMDs was presented. This analysis provided a comprehensive overview of the key conversation topics on this board and how members interacted on it. However, this analysis did not address how participants perceived and understood their experience of using this online group. In particular, it is difficult to extrapolate from message postings why members decided to use the OSG; the factors which influenced their participation after joining; and the potential personal impact of OSG participation for members.

The message posting analysis presented above employed a passive research methodology in that the data analysed were pre-existing online and were not generated by the researcher. This approach garnered data that were immediate, everyday and often spontaneous. However, this approach does not encompass deeper, reflective aspects of the OSG members' experience. Furthermore, Robinson (2001) suggests that internet data, such as participants' contributions to the message board of OSGs, can be supplemented by other sources of data to triangulate research findings. As outlined in Chapter 3, LaCoursiere (2001) advocates the collection of qualitative, particularly phenomenological data from online support group participants. The current chapter adopts this type of qualitative, phenomenological approach to OSG particpants' experiences. It does so in order to complement the previous empirical work in the thesis, accessing elements of the experiences that were beyond the remit of the OSG data. This second empirical element builds an understanding of participants' motivating factors for OSG use and accesses their evaluations of their experiences of information and support on OSGs.

A number of methods are available to gather this type of qualitative information from OSG participants. Internet-based surveys with open-ended questions have been used previously to explore patient and carer

motives for joining online groups and document the experiential advantages and disadvantages of participation (e.g., Coulson & Knibb, 2007; Leonard et al., 2004; Buchanan & Coulson, 2007). While web-based surveys can be useful in terms of garnering a wide range of responses from online support users, due to the asynchronous nature of the research method, there are also demerits to this approach. A disadvantage of using such tools is that the researcher cannot intervene to ask participants to elaborate on a point, nor can they explore unforeseen responses or directions (Flick, 2009).

Online interviewing is another method available to researchers hoping to gain qualitative data from OSG participants. As outlined by Hunt and McHale (2005), online interviewing can have a number of advantages over face-to-face interviews. For example, online interviews may allow researchers to include a wider range of participants compared to face-to-face interviews. Further, participants may potentially discuss sensitive information more easily in an online interview. Online interviewing may also allow both participants and researchers time to reflect on questions and answers, thus mitigating against interviewer effects. However, Hunt and McHale (2005) also highlighted potential disadvantages of online interviewing in that it can prove difficult to maintain focus in online interviews and retain participants' interest over time.

While online interviewing and web-based surveys are options available for researching the experience of OSG members, they were not considered as data collection tools for this study. The researcher had previously experienced difficulties in gaining responses to online surveys in this population and qualitative feedback from surveys was often minimal. Therefore, it was considered that telephone interviews would be an appropriate method of approach. This data collection method had the advantage of accessing a geographically diverse group of participants. This is multiplied by the mobility issues affecting this particular population. By using such an approach, the interviewer was able to reflectively follow up on participant experiences throughout the interview, build rapport and, thus, facilitate the gathering of in-depth qualitative data.

8.2 Methodology

8.2.1 Interview aims and research questions

The purpose of this interview element was to explore how members of an online support group for neuromuscular disorders make sense of their personal experience of using such a support group. In particular, the aims of this study were to explore the context through which members decided to use an online support group for neuromuscular disorders, to explore the factors which affect engagement with the group and to examine the personal meanings participants attribute to their experiences of participating in such a group. The following research questions were posed:

- How do members of an online support group for neuromuscular disorders decide to use this type of support?
- What factors influence members' engagement with the group?
- What personal impact, if any, do members feel the group has on their experience of living with an NMD?

8.2.2 Methodological approach

In line with the aims of exploring members' experiences of using an online support group for neuromuscular disorders, a qualitative approach was adopted to address the research questions. Interpretative Phenomenological Analysis (IPA), a qualitative methodology developed by Smith (1996), was used to inform both the design and analysis of an interview-based study to investigate participant experiences of online support group participation. IPA is a qualitative research methodology that is well suited to examine psychological aspects of participants' subjective experiences, with a focus on understanding cognitions, emotions, feelings, needs, attitudes and beliefs (Smith et al., 2009).

IPA methodology is built on ideas integrated from phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2001). A phenomenological approach in qualitative research involves taking the 'life world' of the participants as the unit of study (Kvale, 1996). Phenomenology is therefore concerned with investigating the nature of participants' lived experiences of particular events. Fundamental

questions asked in phenomenology include: "What is the nature of subjective experiences and how can we conceptualise it?" "What constitutes particular experiences: what do they feel like?" (Stevens, 1996, p.150). IPA is "phenomenological in that it is concerned with an individual's personal perception of an object or an event as opposed to an attempt to produce an objective statement of the object or event itself" (Smith, Jarman & Osborn, 1999 p.218). In this case, where we are concerned with participants' personal interpretations of their experience of using an online support group, this phenomenologically orientated approach is particularly useful.

In IPA research, it is acknowledged that a participant's experience is not transparently accessible from how they articulate their experiences, but that the individual engages in an interpretative process when trying to make sense of their own experience. Additionally, it is acknowledged that in accessing and making sense of participant experiences, the researcher will inevitably create interpretations that are based on their own social and historical perspectives. Thus, it can be said that in employing IPA, the process of analysis involves a "double hermeneutic" (Smith, 2004, p.40). In essence, while the participant is trying to make sense of their everyday experience, the researcher is attempting to understand this sense-making process from their own personal perspective. Central to IPA, then, is the reflexive approach of the researcher in acknowledging their key role in the interpretation of participant experience.

The final central tenet of IPA is a commitment to focusing on the particular, a focus which comes from the theoretical commitment that IPA makes to an idiographic approach to understanding human experience (Smith et al., 2001). Rather than making generalisations about populations, IPA is concerned with the systematic, in-depth analysis of particular experiential phenomena, from the perspective of a particular group of participants, within a specific context (Smith et al., 2009). While remaining idiographic in their focus on particular individual experiences, the small sample sizes used in IPA research also allow for cross-case analysis between several participants (Smith, 2004).

This research is exploratory in that the researcher did not set out to confirm nor disconfirm any pre-existing theories of online support group

use. In line with these exploratory aims in relation to members' experiences of using an online support group, IPA is an appropriate methodology.

The focus on the particular and the idiographic, as well as the inductive analytic process whereby participants are seen as the experts in defining their experience (Reid, Flowers & Larkin, 2005), render the current work compatible with IPA.

8.2.3 Data collection

Semi-structured telephone interviews were used as the data collection method for this element. This method allowed the researcher to investigate, in greater depth, participant experiences of using the OSG. It also afforded the researcher greater flexibility to follow up on unanticipated topics introduced by the participants. The use of telephone interviews, rather than face-to-face interviews, was justified by the fact that OSG participants could potentially reside in disparate geographical areas and had various mobility issues. Telephone interviews were therefore considered most appropriate in facilitating participation.

A semi-structured interview schedule was used to guide the interviews (see Appendix 3). The questions in the interview schedule asked participants to briefly discuss their experience of having a neuromuscular disease, to describe any potential support needs they had and any support sources they currently use (if any), apart from the online support group. The remaining questions focused on participant experiences of using the online support group. Questions were included on participants' past online support experiences (if any), their experience of deciding to use the OSG, their preferences and behaviours in terms of using the board (e.g., posting, reading or sending private messages) and their overall appraisal of using the board (e.g., personal benefits, problems or disadvantages experienced, impact on offline relationships, and intentions regarding future use of the OSG).

Interviews were recorded using a digital recorder after informed consent had been obtained from the participants (see *8.2.6* below for further details). Interviews lasted between 45 and 81 minutes (mean = 56

minutes). Interviews were transcribed verbatim and anonymised for later analysis. Pseudonyms were created for each participant.

8.2.4 Participants

Sampling was purposive in order to recruit participants who had experience of using the online support group under study. Participants were recruited through pilot work that the researcher had previously initiated with members on the online support group under study (see Appendix 4 for further details). Participants who had supplied an e-mail address so that they could be contacted to take part in a follow-up study after this pilot work (n=19) were contacted and sent an invitation (see Appendix 5) to take part in the interview study. A separate advertisement was also placed on the OSG message board, with the permission of the group moderator (see Appendix 6). Participants were asked to e-mail or phone the researcher to indicate their interest in the study.

Those who replied to the study invite were sent an information sheet (see Appendix 7) and an online consent form (see Appendix 8), via the online survey software 'Survey Monkey', to complete prior to undertaking the telephone interview. A mutually convenient time was arranged with participants to conduct the phone interview.

The final group of participants (n=6) were all recruited from the direct e-mails sent to participants who had previously participated in a questionnaire study. No responses were gained from the general advertisement on the message board. This number of participants was deemed an amount sufficient for the purposes of this study, which was to gain an in-depth understanding of the personal experience of using an online support group for neuromuscular disorders. In IPA, the idiographic approach means that this particular analytic method is suited to in-depth analysis of a small number of cases, rather than a large sample (Reid, Flowers & Larkin, 2005; Smith et al., 2009). It is recommended that, for studies using semi-structured interviews, a sample size of between three and six participants is sufficient to meet the commitments of this analytic approach (Smith et al., 2009).

Furthermore, in IPA, it is important that the sample is relatively homogeneous, in terms of meeting the goals of the research question. All

participants in this sample were users of the board. They reported both using the board to read posts and to contribute. Participants had been using the board for between 12 and 18 months with an average duration of 16 months and reported spending between 5 and 12 hours per week (with an average of 7 hours per week) using the board at the time they completed the questionnaire study. Similarly, in terms of number of days per week on which they used the board, participants varied between 1 to 5 days per week, with an average of 3 days per week.

In terms of participants' demographic make-up, all participants were female and their ages ranged from 19 to 51 (mean = 37 years). Half of the participants were single and the three others were in relationships. Most (5/6) lived in urban rather than rural areas. Three participants worked part-time while one participant worked full-time. Two participants reported having retired from work due to ill-health.

Participants had varied types of neuromuscular disorders including limb-girdle muscular dystrophy, hyperkalemic periodic paralysis, facioscapulohumeral muscular dystrophy, mitochondrial myopathy and Laing distal myopathy. The time since diagnosis ranged from 2 to 38 years (mean = 18 years), although some participants noted in their interviews that while their diagnosis may have been more recent, they had symptoms of their condition for a longer time.

8.2.5 The role of the researcher

The researcher was a 27-year-old female health psychology PhD student. She had experience of working with people with neuromuscular disorders through previous volunteer roles. She had no previous experience of using online support groups, but had studied online support group literature and literature relating to coping with a neuromuscular disorder. She had also previously analysed the messages posted to the particular OSG from which the participants were recruited, as part of the current PhD thesis. Therefore, she had an awareness of some of the topics normally discussed on this board. In analysing the resulting interviews, she was careful to try and bracket out this prior knowledge in terms of interpreting participant experiences and continually checked back with participant accounts to verify that the final analysis was grounded in participants' accounts of their particular experiences.

8.2.6 Ethical considerations

A number of key ethical issues were considered when designing, conducting, analysing and writing up the study. As outlined in the data collection procedures above, ethical issues were addressed by providing an information sheet to participants that described the study, the eligibility criteria and the participation process (see Appendix 7). This document also provided information to participants on how they could withdraw from the study or choose not to answer any questions which they did not feel comfortable with. Participants were also informed that their interview transcripts would be stored securely on a password-protected computer, that their responses would be anonymised, with pseudonyms used in place of all given names, and that any identifying information would be removed in all write-ups of the study. Participants were given the contact details of the researcher, should they wish to withdraw their responses from the study at any time.

Prior to participation in the study, participants had to indicate on the online consent form that they had understood the information document, that they were happy to take part in the interview and have the interview recorded, and that they were happy to have quotes from their interview used in a study report (see Appendix 8).

It was not anticipated that participants would find participation in the interviews upsetting. However, it was considered good practice to provide participants with the contact details of the support charity which provided the OSG on the information sheet, should they need any support after taking part in the interview (see Appendix 7).

Ethical approval for the study was gained from the Institute for Work, Health and Organisations Ethics Committee at the University of Nottingham (see Appendix 9).

8.2.7 Data analysis

Data analysis was undertaken following the recommendations of Smith et al. (2009). While IPA proponents often encourage researchers to use a flexible approach to the analysis of data (Smith & Osborn, 2008), there were a number of key stages in the analysis process. The first step in the analysis involved the transcription of the recorded interviews. Carrying

out the interview transcription allowed the researcher to begin to engage with the data and, over time and multiple readings, to become deeply acquainted with the interview material (Bird, 2005).

The next step in the analysis process was to start to interpret the first interview in an in-depth manner. The first level of coding involved open coding on the left-hand margin of the interview, noting down codes which captured descriptive comments related to the semantic meaning of participant comments; comments on particular linguistic features which members used to describe their experiences (e.g., metaphors, comparisons, etc.); and conceptual codes, which captured the researchers thoughts in terms of connecting different parts of the participants' experiences before developing themes. The transcript was then re-read several times and emerging themes were noted on the right-hand margin of the transcript.

After coding the transcript for emergent themes (see coding examples in Appendices 10a - 10c), the themes were listed in a separate document, in order to begin to look for connections between themes and in order to group themes into super-ordinate and sub-ordinate themes. At this stage, some sub-ordinate themes were excluded, depending on their fit with other themes. The list of themes was then tabulated and the themes were checked against the original interview transcripts to ensure that each theme was represented in and stemming from the data. This was done in an attempt to minimise researcher bias (as described by Smith & Eatough, 2006).

This process was repeated for each individual interview, in line with the idiographic approach of IPA. All individual interviews were analysed for emergent themes before a cross-case analysis was completed. A table of master themes (see Appendix 11) was then created to represent the emergent themes across all cases. Before deciding on the final thematic template for the analysis write-up, the researcher revisited all individual transcripts to confirm the prevalence of each theme across cases. This prevalence was noted in the master theme table.

8.3 Analysis

8.3.1 A valued connection to similar others

8.3.1.1 'It's not just me'

Participants described both the context in which they chose to join the online group and their experiences of using the group. In doing so, they discussed how connecting with other members who had similar experiences to them was an important aspect of their online experience. Each participant discussed how the group was beneficial in terms of connecting with people who were going through similar issues that they were experiencing, as articulated by a participant pseudonymously called Elizabeth:

> You get to interact with people who are going through the same thing.

She feels that the internet is advantageous in terms of forming connections with people with similar conditions and getting information regarding her condition:

> I guess the internet makes it a lot easier to get the information that you need or to meet people who have the same condition as you or a similar condition.

Searching for, and achieving this connection with others in similar circumstances seemed to be important for members of the group. They felt that dealing with a neuromuscular disorder could often be an isolating experience, especially due to the rare nature of these conditions and the resulting lack of available opportunities to meet with others with the same condition in daily life. A participant here referred to as Frances captures this sense of relief in connecting with people who have a similar condition by noting the sense of isolation that one can feel when living with a rare condition:

> And the advantage is just like I say em hearing from other people who like have got a similar condition. You know you think you're the only person in the world with it.

Some participants also noted how they felt isolated due to physical constraints that their condition had on their ability to socialise and work and how using the group helped lessen that isolation. Carol, for instance, who experienced restrictions on her social and working life due to her condition, valued the availability of the group as something to engage with when she was on her own at home. When asked whether she felt she had experienced any benefits of using the group, she replies:

> I'm sure it has helped… but if nothing else you know it's something to do when you're on your own. You can go on the computer and…it's something to look at. Do you know what I mean?

She later picks up on this point and describes how using the board lessened her feeling of isolation:

> Em well, yeah well it gives me something to do…It makes you feel not quite so alone…

8.3.1.2 Searching for common experiences

A participant called Bernie, as well as other participants, hoped to use the OSG as a means of connecting to people who had experience of the same condition as them. Prior to using the group, Bernie found it difficult to find someone to talk to who had been diagnosed with the exact condition she had, describing her chances of finding someone fitting this description as 'slim'. She notes that she was pleased to hear that two other people had joined the board that had the same condition as her and she hoped to talk to these members. She values the particular, or as she calls it, the 'very specific' experiences those members will be able to share with her:

> The specific disease I have…is called [disease name]…and apparently that's quite rare so…the chances of me speaking to many people with it…you know are very slim but there's two people on the forum that have just recently said…well I have [disease name] is there anyone like who has that?…And another person and I have got it so it's quite nice and hopefully I'll talk to them….about their experiences because they'll be very specific experiences. It's always nice to hear.

This connection with others with the same condition was valuable for several participants. Similarly, Carol describes how she offered her phone number to another member who had the same condition so as her to keep

in touch as she felt that her condition was one of the more rarely discussed, even on the NMD online group:

> C: I think it was my phone number ... And I think I sent it to someone so they could ring me but we have stayed in... touch by phone, yeah.
> I: Yeah, and like was there anything in particular about that person that you wanted to stay in touch with them?
> C: Just that we had the same thing.
> I: Oh, same condition, yeah.
> C: Yeah, because mine doesn't really get mentioned very much on the forum... There are a lot of people with um [disease name] and... [disease name] things like that...but there's not many people well, there isn't anybody that I know of apart from me and this other lady
> I: Oh, right
> C: with what we've got.

Some members felt that they might be able to gain specific information or solutions from other members who were facing similar issues to them, in terms of coping with their condition. In describing her initial reason for joining the group as an 'information-finding task', Elizabeth started to use the board when she was diagnosed with an illness she thought may be related to her particular neuromuscular disorder. She therefore joined the group to ask whether others had experienced this particular disease in relation to their NMD:

> I think it was basically because about eighteen months ago I was em diagnosed with [disease name] which has a very, very, very vague connection to [participant's NMD type]... and I just wondered if anyone else em had experienced it or you know anyone that had it. It was an information-finding task...I joined and then it kind of escalated from there.

Later in her interview Elizabeth returns to this point about joining the group to ask this specific question. She discusses how she had felt that it would be a 'long shot' to find someone who was able to answer her question, but that she felt the group was potentially the best place to find people who might have an answer for such a specific question about her condition:

> I knew it was a long-shot and em I just thought it can't hurt just because if there was going to be an answer it was more likely to be on there.

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Not all participants were as concerned about meeting someone who specifically had the same condition as them. The OSG moderator, Alicia, for example, noted the potential to learn from members who had all types of conditions. Reflecting on the lay-out of the message board, the moderator describes how she feels it would not be useful to have message threads or sub-boards related to specific conditions. Alicia felt that by focusing too narrowly on each particular condition, members could lose out on learning valuable tips from people with different NMDs:

> If you are thinking upon the idea of having threads to specific conditions… while that's beneficial, while it's got the benefit of you can go straight to an area that deals with your condition, you then don't look at the solutions that other people have had because… somebody's solution with FSH could help somebody who has got Limb-Girdle or Charcot-Marie Tooth or one of the myopathies.

Reflecting the moderator's comments, some participants were interested in meeting others who were similarly affected by their conditions in terms of symptoms and its impact on how they lived their lives, as well as meeting those had a similar progression history to them. As Frances' experience displays, she feels it was not as important to meet those with the same condition but to connect with people who were affected in similar ways by their condition:

> If you're of a similar age it doesn't sort of matter what the condition is…you know the same sort of struggles of getting out and about and things…I don't think it really matters what the condition is.

Some participants discussed solely wanting to see if others online shared common experiences in terms of managing their condition. In the excerpt below, Donna describes posing a question on the board as to whether any members had experienced similar problems with wearing splints as she. She feels that the uniqueness of the conditions that members have means that adaptations are not always specifically designed with the needs of those with NMDs in mind. She feels that those in authority (in her words, 'the powers that be') are not aware of the needs of people with neuromuscular disorders. On posting in the online support group, she questions whether 'there's anyone else in the world' who manages to use the splints that she uses without problems:

I find that em the powers that be...don't recognise these issues. You know they don't understand them. They just don't see how unusual we are...that that the things that they want to provide for us don't work for us. Em I've got a particular problem at the moment with splinting...so it's quite interested to find out whether there's anyone else in the world who wears these damn things who manages to keep them on all night.

Apart from connecting with others with similar diagnoses, symptoms, illness management issues, etc., some participants noted how, over time, they connected with people with similar personal characteristics or interests as they participated more in the online group. For example, Elizabeth describes how she included a link to her Twitter (micro-blogging site) account on her OSG signature and she now 'follows' other members and they, in turn, 'follow' her on Twitter. When asked why she specifically connected with these members outside of the group, she explains that they may have been more regular users of the board and had a similar sense of humour to her. Therefore, it is possible that over time and with regular use of the board, she developed this connection with certain regular participants:

E: my signature on the board has got my Twitter link...em so they so they kind of follow me on Twitter and I follow them back

I: Yeah (.) and were they people that you met first of all on the board that

E: Yeah... and then we started to chat so I know who they are who they are on the board and who they are on Twitter......

I: and em is there kind of anything in particular to those people that you chat a bit more about you know is there any reason why you kind of chatted a bit more to them than other people on the board

E: (.) yeah it it's mainly because they're there more than a lot of people... and I think a couple of them are moderators em and I think we just have the same sense of humour.

8.3.1.3 An understanding audience

A benefit identified by members of sharing experiences of their condition with others on the board was that participants felt that other group members would have a heightened understanding of the particular issues they faced when dealing with their condition on a daily basis. This was a

point made in particular by Elizabeth. She felt that the forum was a useful place to share experiences and information and get responses from those most likely to understand your situation. She feels that while friends may listen to her concerns, they would not 'get it' or understand her experiences in the same way that people on the board would. As Elizabeth puts it:

> It gives you a forum to sort of share your knowledge and experience and to get em response to any concerns you have because I can't go up to someone, em one of my friends, even though they'd listen and they'd probably try to help…if it's something specific to muscle disease they're not going to get it.

She continues later to describe why she finds it useful to vent her feelings about situations related to living with an NMD on the online forum. For example, after describing how she used the board to voice her dissatisfaction with disabled bathrooms in public places, she explains why the board is a unique place where she feels she would have an appropriate audience with whom to share her frustrations. She feels that even if she was to share such stories on Twitter, she would not get the same types of response as many of her friends on Twitter are not disabled. She feels her non-disabled friends may offer sympathy towards her situation but would not be able to offer anything more than that:

> I: Do you find it useful to vent your feelings about those things on the board?
>
> E: Yeah because there's no other real venue for it I mean I could start a blog and write about things like that but who would read it…and would it actually be useful and posting things like that on Twitter I do say stuff on Twitter…but it would just be something that's in passing
>
> I: and you got a good response from that then did you from the people on the board because?
>
> E: Yeah
>
> I: Yeah (.) ok
>
> E: Like I say the majority of my friends on Twitter are able-bodied so they won't really get it they'll go oh that's horrible and I can't believe that but that would be it kind of thing.

Similarly, Bernie noted how members of the board comprised a specifically knowledgeable audience from which she could gain information in the future about relationships and having children. She described herself as someone who tended to respond to other people's information requests rather than ask questions herself. When asked what it might take for her to ask a question of her own on the board, she describes how she generally has all the support she needs from her family in terms of problem-solving in relation to her condition. She may, however, use the board later to discuss the experience of being in a relationship and having children when living with her type of condition. She feels that, when the time comes, she may not want to discuss these more private issues with her parents. She also feels that her existing support network in her family may not have the same understanding of relevant issues as they have not lived with a disability while being in a romantic relationship:

> I: And what do you think it will take for you to kind of you know ask a question on the board of your own?
>
> B: Em, I I don't know (laughs)
>
> I: (laughs) You're not too sure.
>
> B: Eh, I mean we have like when I have a problem and it's like I've got my mum and dad and I've got my sister and my brother… so you've got these four people… that can give you ways and things. So sometimes you know you might not ask but I would ask if there's a problem with something I really didn't want to tell my parents about or something that was more to do with me…like relationships and stuff… you know, things like that. Because sometimes I always wonder how disabled people have managed with their relationships… you know when they have kids and stuff… Things like that I think I would ask on the board rather than because mum and dad obviously aren't disabled and my brother isn't married and my sister… isn't married so…

8.3.1.4 Learning more relevant tips for coping

For most participants, using the board was valued as an opportunity to learn from the experiences of others. The moderator, Alicia, for example, felt that the board was an opportunity to learn from the 'hurdles' members experience and their experiences of progressing symptoms. One

example for her was learning about the system for having carers come in to your home:

> As my condition is going to progress I thought well it's going to be an opportunity to learn from other people and to the situation that they are in… and the things that they have to to face or the hurdles that they've come across

Similarly, Donna discusses how she uses the board specifically in terms of problem-solving in relation to her particular condition:

> I'm interested to to em kind of use if for problem solving…I post specific questions…which are you know which are quite specific to my condition

Members felt that some of the hints and tips gained from those on the board were more likely to be useful than tips gained elsewhere, such as from medical professionals. Elizabeth felt that the chances of effective solutions being given to her on the board by other members were much higher than seeking out those solutions from doctors or nurses. She feels that medical advice may be valuable, but does not always translate to being useful for those with symptoms such as muscle weakness:

> E: If there's someone on the board who has already been through those questions and came up with a solution that works for me you've got a better chance of that working for you as well than something that say a doctor or nurse suggested
>
> I: Yeah so you kind of feel like the kind of information or advice on the board is kind of different from what you might get
>
> E: medically yeah it's just because the problems aren't medical…while a lot of medical advice or information is useful it might not be for someone who has muscle weakness.

Elizabeth also felt that there were often solutions on the boards which members discovered through their experiences, which she may never have thought about previously:

> Sometimes on the boards somebody's already been through that and found something that you would never even think of.

8.3.1.5 Increasing awareness collectively

Members felt that the OSG was a useful platform for raising awareness of NMD issues both for their own personal awareness and for potentially

raising awareness outside the group. Some participants noted how they learned about issues related to NMD without specifically posting questions in order to do so, but by reading about the experiences of others. For example, Elizabeth describes learning about potential issues related to anaesthesiology and having an NMD. She felt that by learning about another member's experiences, she was more aware of potential issues she may have if she is in a similar situation in the future:

> I think one guy is or was going in for an operation and he is going into he was having problems with his anaesthesiologist...and that is not something that I've ever had em to deal with but it was interesting to read...and I don't understand whether eh whether it's a heart thing or whether it's a lung thing....eh and it's something that is if I ever had to be in that situation that it would be useful for me to look at it...because apparently they're scared of your Muscular Dystrophy eh and anaesthesia.

Alicia, the moderator, discussed how she played a part in raising awareness of issues relevant to members on the board in terms of coping with their condition. For example, she discussed posting an article which highlighted government misrepresentation of statistics on disability benefits. She argues that her rationale for posting this was to reinforce the correctness of members' views on the topic and also to generate further discussion:

> A: Yesterday there was a report that came out yesterday that em highlighted the misleading figures that the government was using regarding these changes to disabled benefits... And how these have not been told... they've been massaged and hidden... And yet there is this report this doesn't have itself has not got the publicity behind it... that a government report would have so things like TV news haven't picked it up. Newspapers haven't picked it up...yet you know I mean it did trend on Twitter so you never know somebody somewhere might have seen it... and look in to it and it might get more known that that you know there are misleading, misleading
>
> I: Stats yeah?
>
> A: eh areas to do with eh disability benefits.
>
> I: So that was kind of something that you posted once you when you heard about it?

A: Yeah I posted it on the board. Several had already posted it on Facebook and Twitter but… I did post it on the eh (group name) board yes.

I: And was that kind of just to generate discussion or just to highlight it to people?

A: Well it was a double-sided, it was a two-sided things. A sort of look at this. We're right…This tells us we're right and B. It's kind of like discuss. Have you guys seen this? If not have a read… sort of thing.

Elizabeth hoped that her own and others' postings about issues with which they are dissatisfied might result in more being done to address these issues. In the case below, she is talking about her experience of discussing her dissatisfaction with public disabled toilets on the board. She hopes more of these issues will be discussed so that these issues become more publicly discussed and transparent:

E: People need to start noticing so I'm just and that's the kind of things that I'd like to see more of so maybe something can be done about it…because it just seems kind of ridiculous to call something a facility for a disabled person if a disabled person can't actually use it.

I: Yeah absolutely

E: Who are they consulting if they're consulting anyone? …And there needs to be sort of, it needs to come out of a grey area and become more black and white.

In terms of increasing other people's awareness of NMD outside the group, Bernie also noted how she was willing to relay messages from those using the group to the press through her role as a volunteer. She felt that by using the group, she had a greater knowledge of other people's experiences which she could then raise through her voluntary public relations role:

I do voluntary work. Sometimes I end up talking to the press so…if anyone wants to relay any messages…you know any ideas about what they would want…me to say to the press…because sometimes what if the press asked me some questions about access…I can't just tell them my own experiences because I'm not in a wheelchair…but I am aware of the difficulties that people in wheelchairs have.

8.3.2 A welcoming, social space

8.3.2.1 Feeling welcome

Each participant described how they felt that the board provided a welcoming space for them to join in the conversation. Each member felt welcome to post on the board. Elizabeth describes how the social aspects of the board, such as games, helped people get to know each other by helping to 'break the ice'. She also felt that members of this forum were less likely to be abusive towards each other and call each other names. She contrasts this, as did many other participants, with the potentially hostile nature of some other forums that are not related to NMDs. In Elizabeth's words:

> There was sort of the usual kind of fun and games that you get em on forums like the games and thinks like that…which is always useful to break the ice…….It's just a nice environment because there aren't people saying you're an idiot or em. I bet you can get that on other forums sort of that are nothing to do with muscular dystrophy…no one on there is abusive or anything like that.

Bernie describes how the environment of the group was very inclusive, which she felt it would be, as the group organisers would want people to participate. She felt then that it would be counter-productive if members were anything other than welcoming:

> No-one's, no one's going to be mean. .. It's very inclusive…They want people to participate, you know.

While acknowledging that members' conversations get heated when discussing certain issues, the moderator, Alicia felt that hostility was not taken to a personal level between members. She felt that the mixture of people on the forum and the friendly, non-pressured atmosphere helped to promote this amicable environment:

> We haven't really had anybody that has been very attacking in their defence… you know they've not been very so we've got a good mix of people and that's probably because the air of it is quite it's friendly, social.

Alicia described her role in creating this friendly, welcoming environment. She helped to encourage an inclusive atmosphere by offering

informational support and emotional support to members. For example, she tended to offer reassurance to new members about taking the time to adapt to a new diagnosis, and offered reassurance that members would be there to offer support in answering their questions when needed:

> You've got a little bit of steerage to the main site as to where they can find information... and then em and I'll say it to all of them. I'll say look give yourself time. You are going to be bombarded with information and you cannot take it all in... just give yourself time and you know we're here, ready to help... and we'll answer questions when you're ready to ask them.

Alicia also describes taking care to adapt her conversational style to the needs of new posters. She discussed how she was able to have humorous conversations with some existing members as she had learned about their style over time. Conversely, she took a more cautious approach towards replying to newly diagnosed individuals or relatives due to the stressful time they may be experiencing:

> I do tend to be more cautious if we've got a new poster... eh or somebody who doesn't post very often and definitely it's incredibly cautious and choose words very carefully if you're dealing with somebody who's just been diagnosed... or somebody who is a relative of somebody who's just been diagnosed because they are going to be so bewildered... They are going to feel like you know that their world is spinning so you have to take into account the situation that person is in at the time that they post.

Similarly, she helped to promote a welcoming atmosphere for new members when she developed guidelines for the forum, enabling new members to privately learn how to use the board and not feel exposed by their lack of technical knowledge. She later went on to develop a number of explanatory guides on how to use the functional aspects of the board, basing these guides on commonly asked questions on similar online boards. Alicia felt that these tips could be easily pointed out to new members who may have difficulty understanding how to use the group:

> To have all these guides there and think oh well the common things people ask is how to make the letters bigger... or how to make them a different colour or how do I post a picture and how do I do this. I thought well if I make a list and do individual threads on those then they're all there and they're easy to find ... and you can easily

incorporate it into a welcome message. You get somebody new posting. Hello you know, feel free to post about. If you're not sure what all the buttons mean have a look here and you might find some useful information.

Alicia later explains that she thought this hints and tips guide would be helpful for members who might not like to admit that they don't know how to use certain features of the board, so they could learn in their own time:

A: If its' there [hints and tips guide] then you can direct people to it and they don't have to admit that they don't know what they're doing.

I: Yeah absolutely.

A: They can quietly learn without you know without fear of anybody making comment upon how they do things which we don't fortunately.

She also maintained this inclusive environment by ensuring that regular posters were feeling included and supported on the board. For example, she reports feeling concerned about members who had not posted in the forum for a while or were not as chatty or positive in their posts as they normally were. Alicia describes wanting to reach out the 'hand of friendship', checking in with members when possible to see that they are well:

You get some (members) that that only visit once you know once in a blue moon... and that's fine. That fits in with them but when you get somebody who posts a couple of times a week... or especially if they're a fairly chatty person... and you either find that their posts are a little shorter... or not quite as as jolly... or not there at all and you think well I hope everything is alright... that there isn't something that's worrying them and you then want to do the reach out the hand of friendship ... em thing but not everybody has their emails on their profiles so you can't always contact somebody.

8.3.2.2 A place for interacting 'with the person, not just the condition'

Prior to using the current online support group, Alicia described how she had discontinued using previous NMD online support groups as she felt they were too focused on disability and specific adaptations. The clinical, business-like approach of these groups put her off using these groups, as

they were focused on people's disability rather than their wider personality. For Alicia, it is important in such groups to acknowledge that people are more than their disability:

> I know I looked at one or two (online support groups) but they seemed so focused on the condition that there wasn't much room for the person... Em I'll try and explain it better. I'm not just my disability. There's more to me than my disability...so and I think it's important to recognise that. So to go to a site when all they're talking about is a specific adaption and it's very (.) very business-like... very I don't want to say stand-off-ish because that's wrong but they're just seem to be this this barrier eh very professional. It was like going you know that you would speak to a medical professional... and it kind of lost that personal side. So I didn't use them a great deal.

As part of her moderating role, Alicia was keen to emphasise the importance of this friendly component of the board from the beginning. When she was interviewed for the job of moderator, she emphasised the need to interact with the whole person rather than just discussing their condition. She also emphasised the need for a fun element of the board to help people feel relaxed as she wanted people to feel they would be able to connect with others in a 'we're all in the same boat' style:

> I wanted to get across that you know it is important that we socially interact with the person and not just the condition so that we we have the fun in using things like you know the pet photos or the... quiz type things or the you'll never guess what happened me to me today and so that you understood this person's life not just their condition... but just so that we could exchange views, have discussions on topics, laugh about things, give advice on things and it all comes from a friendly, we're in the same boat style... rather than the professional business style that I'd found boards to be before.

Alicia's experience of the current group was that she was grateful that the group had maintained a friendly atmosphere, noting that her experience with this group has differed in that 'it doesn't feel clinical'.

The more social nature of this forum compared to other forums was also noted by Bernie, who suggested that the group was different from normal. She felt that this difference was due to the fact that the group was there to let people share any problems they have and to potentially provide

emotional support and friendship, as well as to facilitate information sharing:

> It's not a normal forum because people might want to, well they want to talk about normal things like…that are nothing to do with disability but…it's also like a forum not just for information but also to kind of you know eh offload (laugh) you know their issues…that might be going on…you know so it's more, hopefully it will take on more of an emotional support…you know like friends and stuff.

When asked to expand on whether she felt it was helpful that people spoke about topics more broadly than their condition, Bernie suggests that this component is important because she feels people cannot discuss issues related to their condition all of the time.

> I: And do you think that's a good thing or a bad thing?
>
> B: What that they talk about other things?
>
> I: Yeah
>
> B: Yeah yeah because yes well you can't talk about, I don't think you can talk about eh your disability all the time… At some point you're going to not want to talk about it so you want to talk about other things…Yes yeah so it's a good thing

Nevertheless, not all participants were interested in the board as a social outlet. For example, Donna felt that she did not need to use the board in a social way as she could socialise with friends:

> I'm not interested in using it for telling jokes or any of that stuff in fact I can really do without that if I want to socialise…I can socialise with my friends

However, the friendly, welcoming environment was noted by all participants, as outlined earlier.

8.3.2.3 Non-pressured 'coffee shop style' atmosphere

Alicia, the OSG moderator, felt that by facilitating a friendly, welcoming atmosphere, those who feel daunted by taking part may become more comfortable and more likely to participate. She likens the friendly style of the board to that of a coffee shop atmosphere where people can take part in an informal, relaxed environment:

> And it is a it is I am so pleased that it has maintained the friendly, coffee-shop style of atmosphere... because I think that makes it very easy especially for those who are daunted... I think it makes it very easy for them to become comfortable.

Mindful of the different preferences that members have toward taking part in the group, Alicia highlighted the importance of the board being a flexible place for people to participate at different levels (e.g., in terms of posting frequency and disclosure levels):

> It doesn't matter if you're there every day or once a month or... you may only visit once. It's still the same friendly, sit down and tell us what you want, what you don't want that's fine... read what you want, if you don't want that's fine. It's sort of not very, it's not a pressured place in any way at all.

Donna describes this non-pressured environment in a different way. She feels that the nature of the online group provides a less pressurised environment for meeting other people with similar conditions. She appreciates the privacy and control she has over what she reads on the forum. She appreciates being able to control the extent to which she exposes herself to other people's stories, especially when reading about people whose conditions may have progressed further than her own. She describes how it is like being able to 'see in to the future in a non-scary way'. Linking to the importance of privacy and control in her use of the board, she values the inability of others to view her responses and reactions to reading other people's stories on the board. This privacy allows Donna to engage with other people's experiences in a non-pressured way:

> D: I suppose one of the things that using [group name] you can kind of control what you see and what you don't well or you can control your own response to it... and it kind of goes back to that thing you can do it in private... .... There's this thing about it allows you to see into the future in a non-scary way maybe
>
> I: and is that just because you can choose kind of what to read and when you read it or as opposed?
>
> D: I guess...but also nobody's watching your response...you know and you can choose to respond in whatever way you want to.

8.3.3 Gratifying experience of helping others

8.3.3.1 Why not share what you know?

All participants discussed their willingness to share their knowledge and experiences with other members on the board. While not all participants may have started out with the intention of joining the board in order to help others, most noted how they got involved in sharing their experiences when they felt they could contribute. This willingness to help others is summarised by Bernie:

> I would happily help others when figuring out problems.

The moderator, Alicia, discussed how she was particularly conscious of trying to find answers to questions which remained unanswered:

> If I come across one (a post) and it hasn't been answered then yes I will go and look for the information… but if somebody else has already answered it and there's nothing I can add to it then I won't.

Some members were keen to provide information when they felt that they had experience to offer which related to another member's information request. For example, Frances describes how she provided information on her experience at a particular medical centre to help another member who was planning a visit to the same centre:

> If someone was asking the question and it's something, I think there was one where someone was asking about em a medical appointment centre where I'd been myself…what happens there, how long will it take, so I just sort of replied with what happened when I'd gone and how long it took.

8.3.3.2 Feeling useful

Despite Elizabeth not getting a reply to an original question posting, she became actively involved in posting replies to threads initiated by other members. She found this role useful, as she felt that previously she had not realised the wealth of personal experience that she had collected over the years in dealing with her condition. She sees no reason not to 'pass on' her experiences of different issues and any solutions she has found. Elizabeth describes, for example, how sharing information about tricks and tips is useful for her and for other members in terms of both cost-saving on

expensive equipment or saving people the effort of having to fight for access to specialised medical-endorsed equipment:

> It's useful because you don't sort of you don't realise how much you pick up sort of over the years…and em if you've already been through it then why not pass on what you went through and how it was resolved…and it's easier for when you've got a question like I think I mentioned in my question about the wheelchair…em it was useful for me to then post that question for people who have different experiences…and it's useful for them to get that even though it may not be like the medically endorsed answer… It's a trick to find something that you don't have to spend a lot of money on especially on specialised equipment…. or having to fight to get that equipment provided for you.

As a result of sharing her experiences, Elizabeth describes the sense of use she got from helping others:

> Even though I never really got an answer on my original question it was useful to sort of inform people.

When asked how she felt about being able to help others to find and access information, Elizabeth discussed how it was gratifying for her to be able to offer assistance to others so that they did not have to struggle as much with condition-related issues. She continues by noting that it feels good to be able to offer assistance to those in the group, as she doesn't have many disabled friends to whom she can offer this help outside of the online group. Elizabeth feels that her non-disabled friends wouldn't share these types of issues:

> Em it's really gratifying in a way I suppose em…because I don't have em that many disabled friends and em…it's it's my friends don't really get it but that's that's fair enough for them. I don't have all their kind of problems on their kinds of things and just to pass on any eh knowledge or just try to make their life easier…because why bother to fight when there's an easy way around it?

Similarly, the moderator, Alicia, also discussed the sense of feeling useful to others through her role in the group. By using some of the forum-related skills she had developed on other online groups, she felt she could improve the experiences of group members. Previous feedback from other

online groups suggested that Alicia's answers regarding use of the board were easy to follow, so the current group was a chance to utilise these skills to their full potential or to 'let rip with that skill':

> On some boards you will get somebody who will ask straight out 'how do I do this?' ... And I would find you know would write the answer out and I was getting the sort of feedback that said that people were finding my answers easy to follow... that they could learn from them so I was like well this is a skill... and [group name] was an opportunity to let rip with that skill as it were.

In terms of feeling useful in her role, Alicia discussed how she had also received positive feedback that suggested that her advice had been useful to newly diagnosed members. She felt especially encouraged by these comments given that new members are in particular need of careful attention:

> I'll say look give yourself time. You are going to be bombarded with information and you cannot take it all in... just give yourself time and you know we're here, ready to help... and we'll answer questions when you're ready to ask them... and we've had one or two that have done that and have been you know very em very encouraging...to us that we've helped or that they found what we said useful.

Alicia hoped to continue in her role as moderator for the foreseeable future as she was enjoying the role. She felt that she was getting dual benefit from using the board in terms of using the board herself and feeling useful to others:

> I: And do you think that you'll stay as a moderator for the foreseeable future
>
> A: Yeah yeah I found that I am enjoying it and I you know I am getting a sense of em use... from it. I feel useful... as well as it's useful to do. You know it's useful to me as well as I'm useful to others so yes yeah as long as they'll have me I will.

The only potential limitation of offering advice, mentioned by one participant, was in not knowing if the advice given was useful for others. Bernie notes that she doesn't always know whether she has been helpful to others if the question poster does not reply:

B: Some people like might post a problem. You might reply they might not reply at all so you don't always know if…helped or not.

8.3.4 A support source with limits

8.3.4.1 'They can just tell me their experiences but that's kind of it'

While the group was seen as a helpful place by participants, members mentioned limitations to the extent to which they felt it was beneficial. Donna felt that while the support on the group is helpful, it does not fully meet the support needs of people affected by these disorders. Donna feels that the board is limited to information sharing between members and does not feel that this support is a replacement for that which can be gained from a health professional such as an occupational therapist:

> Yeah although I think there are limitations in terms of what you know they can just they can tell me their experience you know but that that's kind of it…Eh I don't think I don't think they're a replacement for the kind of perhaps the psychological support and challenge…that you might get from someone who is it's for instance an O.T. who is able to do some of that.

When asked further about what she feels is different about the information received on the group, Donna continues by noting that participants on the board may not challenge each other when they have different opinions, as they are trying to maintain a polite atmosphere on the board. She therefore thinks that people are unlikely to challenge each other and disagree on topics. In summary, Donna feels that the board may not be able to answer all the questions she may have, but she does feel that it 'goes some way' towards meeting her needs:

> I: So you think you're getting more of people's experiences rather than specific kind of information or?
> D: Eh (.) well you know people are going to be polite to each other on there, aren't they?…… I just think that people are probably quite respectful of others' opinions and while they might disagree they might not challenge each other or…which sometimes is quite useful to have. But I don't think that it answers all of, I don't think it meets all of the needs but I think it goes some way…to meeting them.

Donna's sentiments are also echoed by Bernie, who is ambiguous about the extent to which she thinks the forum can actually help members. Bernie thinks that the benefit gained is likely to vary based on the member's age; who is giving advice; and what types of advice are exchanged:

> I don't know em to what extent it really helps... You know it really depends on your age... and who, what advice they give you know.

She also felt that, although she was happy to listen to other people discuss difficult issues in terms of dealing with their condition, there are only limited ways in which members could help each other. Due to massive variation in experiences that members have in terms of access to appropriate care and other services, there are obstacles to providing real, practical help. She notes how the 'postcode lottery' means that not all members share equal access to appropriate services and this causes inequality in members' experiences. In the face of these overarching differences in members' experiences, Bernie feels there is little that members can do on an online support group to help one another:

> B: And sometimes if someone just wants to rant about... bad times you know, it's just nice to let them do that and then... kind of agree with them because a lot of people eh they have, they don't have access to certain caring and all that... and people do. It's like a postcode lottery... kind of idea. If you're not in a certain postcode then you might not get the, the... you know what you're entitled to.
>
> I: So do you think that people's experiences are varying then on the, on the
>
> B: Yeah yeah
>
> I: forum because of that.
>
> B: Some people have really good experiences and some people won't have very good experiences... You know. There's only so much you can really do...on a forum really.

Bernie feels that one way in which the board could be made more useful is if more professional input was encouraged. This input, she feels, would help members to navigate social issues such as dealing with discrimination and dealing with benefits. She feels that these are issues which members may not necessarily be equipped to help each other with.

Again, noting that members are limited in that they can 'only do so much' to help one another on these issues, she feels there is room for improvement on the board in terms of getting expert advice from professionals. In Bernie's opinion, it would be ideal if the board were to adopt a kind of 'citizen's advice' type model to help members deal with specific issues where they need expert help:

> B: There's a section for like professionals and... you've got a section for carers and stuff and hopefully if you get more, if you get more participation from... the professionals on it that would be even better.
>
> I: And do you think that's just in terms of information or?
>
> B: Information, problem-solving like it would be really good to get like a legal expert in like because I think there's things like discrimination like what people are, like I would like, I would like (group name) to be almost like a citizen's advice kind of... because there's lots of things on em you know what benefits you're entitled to, things like that. People are a bit, they don't always know... unless they have some people involved specifically like in advocacy or... you know?
>
> I: So do you think it would be better to have someone who kind of had a bit more background?
>
> B: Yes yeah like a yeah, yeah, a sort of
>
> I: And do you find that people are able to give each other advice on that kind of, on those [issues]
>
> B: [Yeah] like I mean we can only do so much obviously... so it would be better if you had, if you had legal questions if you could like an actual... lawyer or someone on there.

8.3.4.2 Privacy concerns impacting engagement

While only mentioned specifically by one participant, one limitation of the group which affected engagement was a concern about privacy. Frances felt that one of the disadvantages was the potential for people who know her offline to find and read her posts on the internet:

> The disadvantages are sort of I don't want to someone to read something about me.

She describes her intention to engage more frequently with the board, but is always cautious about doing so, or takes longer to formulate a response as she takes a 'guarded' approach to posting on the internet. As the group is publicly accessible, she is aware that you can never be sure who your audience is when you add a post to the board. Due to these concerns,

Frances reports being particularly careful not to disclose very personal issues on the board:

> I always intend to use it a lot more than I do…and it's just it's just a matter of em time and em sort of also I'm sometimes a bit guarded about what I say on forums…because you're never quite sure who might read your answers you know what I mean…you might be so I'm quite careful about what I might if there was any sort of particularly personal issue or something I probably wouldn't use it.

8.3.4.3 Difficulty navigating board

A further issue relating to the limitations of the board, mentioned by one individual, was a difficulty navigating through the information on the board. Donna found it difficult to access new messages posted in threads, especially when she had been away from the group for some time. Due to the fact that the messages appear in order of posting, Donna found it difficult to find any new updated post without going through the whole thread to do so:

> The message display I find very annoying because you can't, it's quite hard to you know eh you know I might I might log on once or twice a week…and I'd see what activity had been since I'd been away… em those messages don't seem to appear in you know post order and then you see the whole you know all of the threads…em in that post and I find it annoying the way it always displays the first post in a thread first.

8.3.4.4 Difficulty relating to others

Despite the fact that participants discussed the values of connection with similar others (as outlined in the first theme), there were still instances where participants felt in some way different from other members, which affected their engagement with the group. This difficulty was apparent in a number of different guises.

One such guise is represented in Frances' experience of feeling 'out of the loop' because she wasn't as regular a poster as others. She felt that as others had probably developed stronger relationships and had 'gotten to know each other' over time, Frances felt less involved and 'less part' of the group:

> Sometimes I think I feel a bit like not part of it (.) you know because I don't post often…you sort of feel like em that regular posters that have

> kind of gotten to know each other a bit more and you kind of feel a bit like you're sort of interjecting on someone else's conversation almost.

Frances felt that others may be more fluid posters in that they may be able to write or 'fire-off' posts more quickly than she can. She, on the other hand, as pointed out in the previous subtheme, worries about writing posts that will end up in the public domain and therefore takes time to consider her responses:

> I mean not having the time is not really an excuse because I have got the time. It's just...getting around to it it takes me quite a while as well...because you know a lot I think a lot of people just fire off really quickly and I'm kind of a bit how does that sound when I've written it or...is that what I really mean to say I know it's quite an informal way but I'm just so so kind of in to check really carefully what I'm saying and writing and am I spelling things right...so yeah it's difficult to kind of get into a more free way of sort of chatting online.

There were several other ways in which participants made comparisons between their situation and others that impacted on how they used the board. Elizabeth feels that there are limits, for example, to the level with which she can share experiences with people who are newly diagnosed. She feels she can only share experiences 'to an extent' with those who have been more recently diagnosed as she has had her condition since childhood. Elizabeth feels that her experience is different because she has always had her condition:

> A lot of the people on the board are older than me but there are some around my age that have just been diagnosed so I don't know I can explain to them to an extent what I went through with my diagnosis because it's always been there it's been a different experience for me.

Bernie felt that due to differences between her experiences and those of other members of the board, she chose to generally reply to posts rather than discuss any particular problems she was having:

> A lot of these types of things are in my past...rather than my present so that's probably why I don't post about them because they've already happened so... you know, it's not a problem anymore.......

> A lot of people would be posting because it's happening right at that point... you know whereas for me it's in the past. I can give them advice on how to handle it... or how not to handle it.

Bernie feels that the issues she is currently faced with may be too particular or too 'specific' for others to be able to answer:

> I preferred (.) you know I preferred to reply actually... more than post a topic because you know some of the issues are just ah very specific...I always feel like well (.) there's no point. I'm not going to get a solution for some of the problems that I have.

Similarly, Carol found that perceived differences between her level of disability and other members' levels of disability influenced her use of the group. She uses the word 'fraud' to describe how she sometimes feels that she does not belong in the group because her condition is not as severe as that of others:

> When I go on [group name] I almost feel like a fraud because some of the people on there are worse off than me...What have I got to complain about when they've got so much to put up with?

Carol finds it difficult to relate to others because she feels her situation in managing her illness is quite different to others because she has more familial support. Due to this perceived difference, she tends to read rather than post on the board:

> I think I probably, I probably I go on it quite a lot to read it but I don't make that many contributions... because I feel ah (.) sometimes I feel like I can't relate to some of the other peoples' problems because I think well I've got my husband, a lot of people are on their own, and they have PAs and carers and all this and I think my situation is quite different from theirs...Em so I can't really relate.

A further difficulty, identified by two participants, in terms of relating to other members was the feeling that their political interests were not aligned with those of other board members. This affected their level of engagement with the group. Donna, for instance, describes how some group members are not as aware of disability issues as other members of other forums. Therefore, she feels that the forum is less political in that sense than she would have hoped:

> I: And is there any reason why you kind of prefer to use a more general disability forum than say [group name] for those kinds of things (general disability issues)?

> D: Yeah probably because I think the people are more political and more disability savvy.

Donna later describes how she feels that group members concentrate mainly on the particular problems faced in dealing with their condition, rather than, as she suggests, being 'aware of the bigger political stuff':

> Em I think perhaps on [group name] I think people are quite focussed on their impairment the specifics of living…their lives they're not really aware of the bigger political stuff.

On the other hand, Carol felt that the group was already quite political in nature. She, however, is not interested in politics and finds that she sometimes struggles to relate to what people are talking about when they discuss particular issues:

> Some of the things that uh go on the website can be pretty political… and I'm not really into politics at all… em some of the things that some people write on there I don't I don't really understand what they're on about (laughs).

Consequently, Carol sometimes did not engage with the board because she felt she did not have the energy to compete with those who have strong views which are different from her own:

> C: I don't post an awful lot because… em (.) sometimes I want to say things that I if I posted I would say something quite controversial
> I: (laughs)
> C: and I can't be bothered (laughs).
> I: So, is it that you would not like to deal with what people say after that or you feel like it's just (laughs) too controversial to put it down?
> C: Sometimes I think, yeah because I think quite often I think well I've got a different view on things than a lot of people…and I can't be bothered. I haven't got the energy… to argue with people do you know what I mean?

8.4 Discussion

The purpose of this study was to explore how members of an online support group for neuromuscular disorders made sense of their personal experiences of using an internet-based support group. In particular, the aims were to explore the context through which members decided to use

this online support group; to examine factors which influenced members engagement with the group; and to explore any personal impact that using the group had on members. These aims were fulfilled by using a qualitative exploratory research design to explore the in-depth experiences of six members of a particular online support group.

The three emergent themes suggested that the board was a place where members found a valued connection to others who were in a similar situation to them; where they felt welcomed and able to discuss issues both related to their illness and their lives in general; and where they felt gratified by experiences of helping other members. While valuing the group as a supportive place, participant experiences also highlighted certain limitations to the usefulness of this NMD online group.

In terms of the valued connection members found with those in similar circumstances, it was apparent that members experienced considerable difficulties in meeting other people who either had the same (or similar) conditions as them beyond the online context. Thus, it seemed that for these members who had rare disorders, the connections made through this online support group were highly prized. Users of the group discussed how this connection made them feel less isolated, and how they felt that members could understand them in a way that other (even highly motivated) people could not. Members reported that participation in the OSG allowed them to gain access to a wealth of relevant information for coping with their condition. They also felt that the specialised, personal tips and help exchanged between OSG members were potentially more beneficial than those gained elsewhere, e.g., from medical professionals.

This valued connection to others with similar conditions confirms the value of peer support for those living with NMDs and highlights the importance of this novel medium of support for those who traditionally find access to support difficult due to their physical disability and the rare nature of their disorders. As cited in Chapter 2, peer support was also one of the main benefits of a group exercise intervention where participants with MD valued contact with other people with their condition (Wenneberg et al., 2006). Similarly, participation in a group rehabilitation programme lessened NMD participants' feelings of isolation (Nätterlund & Ahlström, 1999) and attendance at a specialist neuromuscular clinic was

beneficial for patients in terms of interacting socially with others with their condition and learning about others' coping strategies (Hartley et al., 2011).

Despite wanting to connect to people who had similar experiences, it was interesting that perceived differences between members and others was a factor which inhibited some participants from engaging with the board as often as they might have liked. Ways in which members felt different from others included their political views, their participation level, and their level of disability compared to others. It is difficult to see how this sort of limitation can be removed from the OSG as, by its very nature, it attracts people who vary in terms of their illness progression; the time they can contribute to the forum; and the level of political interest and activity represented. An alternative that might mitigate against the effect of varying illness progression as a use inhibitor would be to separate the OSG into progession pathways that categorises members according to their level of disease progression. Though this approach would offset the inhibitions to use caused by variety in disease progression on the OSG, it would also dilute a range of advantageous elements described by participants. Throughout the analysis, participants described the representation of different levels and types of NMDs on the OSG as offering a glimpse into the future progression of their condition; as affording tips and ideas that apply across levels and types of NMDs; and gaining general advice issues that are not tied to a condition, e.g., maintaining a romantic relationship, to name but a few.

Regarding the political bent of the OSG, it may be the case that this particular board was more politically motivated due to the fact that it was part of a service provided by a charity devoted to improving neuromuscular care. Participants felt that the board provided a platform for raising awareness about NMDs, which is reflective of the 'collective action' construct of the empowering outcomes of online support participation developed by van Uden-Kraan, Drossaert, Taal, Shaw et al. (2008). Evidence for this construct was found in this analysis in that the OSG membership facilitated a community-based approach to raising awareness of medical, personal and political issues. This study addresses the authors' call in the above-cited paper for OSG research to consider

empowerment as a collective experience that can be fostered in OSGs rather than a personal attibute of individual OSG members.

Interestingly, while OSG members in this study found that comparisons with other members inhibited their use of the group in certain ways, other researchers have found that OSG members sometimes report benefits from making comparisons between themselves and other members. For example, some OSG users have reported feeling better about their illness by making downward comparisons to other members who are more severely affected (e.g., Hadert & Rodham, 2008; van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008). As many of the participants in this study had experienced long-term diagnoses of their illnesses, it is possible that they were not able to use downward comparisons in this way as they may have been more severely affected by their condition than other members in the group.

A limitation mentioned by members was that they felt that there was only so much that could be done to support people with NMDs in an online setting. This limitation may reflect the need for further, more professional support that cannot be met by a peer support group. Some of the issues related to how the board was designed, such as the concerns two members had about privacy, have been raised previously (e.g., Nonnecke & Preece, 2001). Privacy issues and navigating issues are problems which could be dealt with by changing privacy and control settings on the group website. Changing the privacy settings of a group, however, may change the dynamic of the group and individuals who may want to lurk on the group instead of joining may be lost.

A clear benefit of using the group for members was the ability to help other people. This benefit has previously been raised in other online support group literature, as members feel valued by helping others (e.g., Perron, 2002; van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008), and relates to the 'helper therapy principle' (Reissman, 1965), which suggests that support group members who help others may benefit therapeutically from such interactions. Members reported a sense of usefulness from helping other people and hoped that they could help others avoid some of the difficult experiences that people can have in coping with an NMD. While most members valued the social space provided on the OSG, some

individuals still expressed an interest in using the board in a more instrumental way in terms of discussing items related to their NMD. This serves to show the highly individualised preferences participants may have when using OSGs.

The experience of the OSG moderator was particularly apparent in the theme 'a welcoming, social space'. It was clear that she was highly motivated to provide a sociable, friendly and welcoming environment to all other members. While it is impossible to attribute other members' appreciation of the social environment purely to the work of this one moderator, it is clear that moderators may have an important role in setting the tone of the forum discussions.

As both OSG co-ordinator and NMD sufferer, the moderator provided an interesting case for this analysis. The interview analysis represents three different stakeholders in the OSG environment: that of the moderator, the user and the moderator-as-user (within the moderator's experience itself and across participant accounts) and this provides a broad, multi-perspective understanding of the OSG setting. The inclusion of the moderator's perspective in analysing OSG member experience is significant and unique in that it encompasses a more rounded perspective than is normally presented. Van Uden-Kraan et al. (2010) studied the motivating factors and intentions of moderators on OSGs for those affected by breast cancer, fibromyalgia and arthritis. However, the experience of the OSG users on these moderators' sites was not explored in van Uden-Kraans et al.'s study. Thus, the experiences of the moderator, user and moderator-as-user – presented simultaneously and explored qualitatively – are unique to the current thesis.

Furthermore, the fact that this more holistic, multi-perspective view on OSGs was analysed with an in-depth methodological approach means that there is a depth and breadth to the current analysis that is rare in the literature. It was particularly interesting to compare the moderator's intentions and aspirations for the site with the actual experiences of the users. This aspect of the study, in particular, would make for interesting future research in the area.

There are a number of methodological issues which should be considered when interpreting the results of this study. All participants who agreed to take part were female; therefore it was not possible to investigate whether or not male group users share similar experiences. All participants were self-selected into the study and had previously participated in a questionnaire study that the researcher had posted on the OSG board. This group of participants may also be highly motivated to take part in this research and therefore may represent those who are especially enthusiastic about the online support group and the study of NMD more broadly in academic research. The awareness of political attitudes to disability in the data, as well as the frequent referral to the paucity of public awareness of NMDs, suggest that the participants are likely to engage in research in order to raise the profile of NMDs and disability issues more broadly.

All participants had an NMD, therefore the experience of carers and was not explored in this interview study. Carers may have different motivations for using the OSG and their experiences may differ from people affected by NMDs. Previous research has suggested that parental carers in DMD benefit from support group participation, feeling a sense of belonging and empowerment in their involvement in support group activities (Hodges & Dibbs, 2010). It would be useful to know whether these benefits also occur for carers using NMD OSGs. The lack of carers replying to the recruitment techniques in this study meant that this perspective was not represented in the analysis.

All participants were active users of the OSG in that they read and posted messages on the board. The data represented various levels of involvement on the OSG, ranging from the extremely active role of the moderator to the infrequent poster who mostly engages through reading others' posts. However, there is another level of involvement not covered by this analysis. It would be interesting to investigate the experiences of those whose only engagement on the OSG is to lurk. This lurker perspective represents an extreme passive involvement with the OSG, the quality and usefulness of which should be studied in this OSG in order to encompass the full range of member involvement. In particular, it would be useful to see if the limitations mentioned by participants in this study are experienced as barriers to participation by lurkers. In summary, the

views of participants in this study may not be representative of all types of users on the board.

As this study was based on one particular OSG, it is also difficult to make wide generalisations from this exploratory study. However, the detailed, data-driven analysis of the personal stories of six OSG members represents a richness and depth that offsets this lack of generalisability. Indeed, it has often been argued that such rich qualitative accounts operate under a different set of methodological assumptions and expectations than those methods whose value lies in their generalisability (Flick, 2009; Kvale, 1996).

The results of this study show the potential benefits that an online support group can have in terms of helping people with rare conditions to connect with people experiencing similar life circumstances. This connection was highly valued for the unique understanding that members shared in relation to coping with these conditions; and the highly relevant tips that were exchanged based on participants' personal experiences. This particular online support group was valued for its friendly, welcoming atmosphere. While members were generally positive about their experiences of online support, the limitations pointed out by members suggest the need for further research into the limitations of OSGs as a support medium.

Chapter 9: Overall Discussion

9.1 Thesis contribution

The broad aim of this thesis was to examine the potential role of a new online support group for people affected by NMDs within the U.K. In particular, this study aimed to examine how members used this new online message board and to explore participants' personal experiences of being members of this OSG.

This thesis provided a detailed, previously unexplored, insight into the role of OSGs in meeting the needs of people affected by NMDs. The results of this thesis provide a timely contribution to the gap in the literature pertaining to this novel support medium for people affected by NMDs.

The remainder of this chapter will present a summary of the main findings in relation to the research aims and with reference to OSG and NMD literature. This will be followed by a discussion of methodological issues and considerations to inform future research in this area. A presentation of some of the clinical implications of this research is also included.

9.2 Summary and discussion of main findings

The study aims were addressed in two qualitative, empirical studies. The first empirical element inductively analysed postings to an online support group for those affected by neuromuscular disorders. The second empirical element was an in-depth interview study of members' personal experiences of this NMD OSG. A phenomenological epistemological perspective was applied throughout.

Conducting a data-driven message postings analysis allowed a unique insight into how members used the OSG in the early stages of the group's development, especially in terms of how OSG members established a sense of community and sharing. The analysis demonstrated how members initially established themselves on the group by disclosing personal information. Evidence from linguistic studies suggests that personal disclosure of illness-related information can serve an important

function in legitimising new members' participation in an OSG (Armstrong et al., 2012; Stommel & Meijman, 2011). Similarly, self-disclosure has also been identified previously as a key therapeutic factor in OSG communication (Winzelberg, 1997; Klaw et al., 2000; Tichon & Shapiro, 2003). The findings of this study suggest that disclosure processes are particularly important in the formation stages of an online support group.

A further process in this introductory phase involved OSG members searching for connections with people with similar illness experiences (e.g., diagnosis, progression history, similar symptoms) or those with similar interests. Seeking these connections with similar members has been associated with the creation and maintenance of solidarity in online groups (Armstrong et al., 2012). In particular, new members in this group seemed to have particular difficulties in meeting people with their condition or a similar condition offline, which is consistent with research presented in Chapter 2 (sections 2.6.3 and 2.7.3) regarding the socially isolating experience of living with and caring for people affected by these rare disorders (e.g., Boström et al., 2005; Mah et al., 2008).

A further important aspect of community building within the group was members' sharing of aspirations for the development of a resourceful community for the members. The instillation of hope in terms of developing a community may have helped to provide a common, binding sense of purpose for the group in this early developmental stage.

In members' introductory posts, the topic of diagnosis experiences was a common one, in terms of both disclosing personal experiences and sharing support on the topic. However, not all posters had newly diagnosed conditions. Therefore, a recent diagnosis or change in health status did not seem to be an initiating factor for OSG use by all members in this study, as was suggested by LaCoursiere (2001). Nonetheless, diagnosis narratives were an important part of the introductory process. Describing their relationship to their illness may have served as an important legitimisation process to help members integrate in to the group (Stommel & Meijman, 2011).

While the discussion of diagnosis experiences is a common aspect of OSG communication, the particular narratives in members' discussions on this

group were related to delayed diagnosis, a theme which is evident in the NMD literature (see Chapter 2, e.g., Webb, 2005; Plumridge et al., 2010). Members with a long-standing diagnosis also supported those with new diagnoses, validating their experiences and emotions; and providing emotional and informational support, which are common types of supportive communication in online groups (e.g., Coulson et al., 2007; Mo & Coulson, 2008).

The results of the interview component of this thesis showed how members valued the connection the OSG gave them to people in similar situations to theirs. Knowing they were not the only one with their particular condition was appreciated by members who sought out others with similar conditions, symptoms, progression or those with similar interests/views. The importance of finding a sense of recognition through online support group use has been previously identified as a potential empowering process related to participation (van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008; van Uden-Kraan et al., 2009). The OSG was particularly valued in terms of providing an understanding audience for members who often experienced a lack of understanding of their condition from others (e.g., health professionals, relatives and friends).

Interviewees valued the social, friendly atmosphere on the board, which they felt was a welcoming, pressure-free place for interacting with their peers. Early computer-mediated-communication literature (e.g., Kiesler, Siegel & McGuire, 1984; Short et al., 1976) suggested that communication online may be less personal due to the lack of social cues. In this thesis, it is clear that a key function of the group, especially in the early stages, was to welcome new members, create common ground and share experiences and support. The interview study reinforced the message posting analysis in highlighting the importance of this social atmosphere as a key feature influencing members' satisfaction and engagement with the group. Thus, it seems that participants interacted in a highly personal manner, regardless of the apparent lack of social cues.

Other limitations suggested to be specific to communication in online groups include the potential for an anonymous environment to facilitate anti-social behaviour such as flaming or misunderstandings between participants due to the lack of verbal cues (White & Dorman, 2001;

Wright, 2000; Wright & Bell, 2003; Sproull & Kiesler, 1986). These problems were not mentioned by interviewees, nor were they evident in the message posting analysis. This may again relate back to the evidently friendly, social environment of the OSG and the (initial) information-driven goals of members. The nurturing of a sense of community and problem-sharing, and the personal connections generated therein, may have also mitigated against anti-social behaviour.

Weak tie theory (Wright & Bell, 2003) suggests that online communication may be particularly useful in terms of developing 'weak ties', which can be useful in terms of garnering information from a heterogenous group of people. As noted earlier, and in line with weak tie theory, members valued the OSG as a rich source of experiential information from a variety of people affected by NMDs. However, contrary to weak tie theory, participants also discussed how they had developed or hoped to develop relationships online (e.g., through other social networking sites) or offline with other OSG members. This suggests that the ties people sought or received were not necessarily weak, but could over time develop into strong connections. It could be argued that it is very unlikely for people with very rare conditions to meet each other in any context. Thus, the likelihood of the development of strong tie relationships between these people is amplified. It is therefore reasonable to imagine that mutual exposure to a rare, chronic illness experience (e.g., experience of a rare NMD) would make for a strong relational tie, regardless of on or offline setting.

The detailed, idiographic analysis characteristic of IPA methodology allowed the researcher to illuminate commonalities in interviewee experiences, whilst being sensitive to the individual experience of each member. This was particularly useful in terms of highlighting the role of the moderator in facilitating this social, friendly environment which was prized by other interview participants. The moderator highlighted her conscious, deliberate efforts to create a friendly atmosphere so people could discuss issues beyond their disability. Findings from this thesis suggest that moderators may have a key role in creating and maintaining this friendly environment, although this suggestion would need to be explored further in future studies.

The analysis of message postings also provided an interesting insight into how members shared concerns about symptoms, sought information and shared knowledge on symptom interpretation and management. Such discussions are commonplace in OSG interactions (e.g., Armstrong et al., 2012; Barney et al., 2011; Springer et al., 2011). The particular focus in this OSG was the sharing of information and emotional support in relation to: dealing with emotional reactions to often progressive symptoms; the resulting need (and reluctance) to use adaptations or aids; and the sense of isolation incurred when managing a rare disorder. In particular, participants used the OSG to check the normality or otherwise of their symptoms. The OSG provided a particularly important forum for members to receive feedback on their symptoms. Due to a lack of understanding and recognition of their symptoms and conditions, participants often felt significant isolation in coping with their conditions, and the OSG helped to lessen this effect.

In terms of symptom management, support was offered through informational sharing, validating/normalising experiences, as well as through encouraging each other to take a positive and pro-active attitude towards managing the condition and embracing the use of supportive adaptations or services. The exchange of tips in coping with both the psychological and physical impact of symptoms was mentioned by participants in the interviews as being particularly valuable due to the informal, experiential nature of the information exchanged and the mutual understanding of group members. Interviewees noted how they valued the opportunity to learn from other group members in terms of coping with their condition and felt better informed through participating in such groups, findings which are consistent with previous research (e.g., Pfeil et al., 2009; van Uden-Kraan et al., 2009).

The gratifying experience of helping others was highlighted as a main theme in participant accounts of their OSG use, which supports previous research (e.g., Winefield, 2006). Members discussed the importance of sharing their personal experience so other people could benefit from this experience, and felt useful by being able to help others.

One potential disadvantage of communication in OSGs is the delayed feedback which can result from asynchronous communication (Wright,

2002). In the case of one participant in the interview study, delayed feedback meant that she did not always know whether she had helped those she offered advice to. The asynchronous nature of online communication within these groups, and the fact that people can leave the group at any time, may temper the experience of helping others and, in this sense, may make this experience different from face-to-face interactions.

A final aspect of the thematic analysis of message postings revealed an interesting and novel insight into how members discussed the societal and political aspects of living with an NMD. Such aspects of online support communication are not normally illuminated through studies which have focused purely on social support processes or therapeutic processes in online support groups. Thus, the data-driven approach in this thesis was useful in terms of illuminating these unanticipated topics. Members discussed the difficulties they experienced in terms of the lack of understanding they faced when dealing with people who are not aware of their disability and voiced discontent at Government and media presentations of disabled people.

The board was used as a platform to raise discussion and awareness about different societal and political issues related to living with a disability. Sharing ideas about ways in which the profile of NMDs could be raised was valued by members. This aspect of the thematic analysis suggests that the OSG may have a particularly important function in terms of helping people affected by these rare disorders to discuss difficulties related to living with a condition that is not widely recognised. However, some of the issues discussed also related to the general experience of being disabled and political discussions of this nature have been found on other online support groups (e.g., Peterson, 2009).

Interview participants noted how they felt that the board was as a useful platform for raising awareness of issues affecting people with NMDs, often using the board to discuss personal experiences which were problematic due to a lack of such awareness. Previous OSG research has suggested that members find participation useful in terms of venting their feelings, which can have a cathartic effect (e.g., Pennebaker & Beall, 1986; Sheese, Brown & Graziano, 2004; Lieberman & Goldstein, 2006; Yalom, 1995). The ability to vent these issues, in the company of people who are likely to

understand their experience, was highly prized among interviewees. Some members felt that there was no other platform for discussing some issues which related specifically to NMDs.

The importance that interviewees ascribed to having a receptive, understanding audience highlights that, although disclosing personal information and illness experience may provide important benefits to OSG participation, it is not just the act of writing that is beneficial to this process of disclosure. Thus, it is unlikely that the expressive writing paradigm (e.g., Pennebaker, 1993; Pennebaker & Seagal, 1999) can wholly account for any potential benefits of increased disclosure in OSGs found in some previous studies (Lieberman, 2007; Shaw et al., 2008).

The interview component was particularly useful in highlighting perceived limitations of online support experienced by users, which is an under-researched area in OSG use. The findings from this interview study are particularly useful in addressing this research gap, as participants discussed how the OSG could provide support within limits. In this sense, participants felt that although members could provide valuable assistance and support to one another, this support could only go so far in terms of meeting the needs of members. Some participants felt that the OSG could not be a substitute for professional health or social care input.

Difficulty in terms of their ability to relate to others in the group (e.g., due to having varying disability levels; different disease progression histories; and different views on politics and other interests) also influenced the degree of interaction members engaged in and the perceived benefits of the group for them. In previous research, it has been suggested that people may sometimes feel better by making downward comparisons in online groups (Hadert & Rodham, 2008; van Uden-Kraan, Drossaert, Taal, Shaw et al., 2008), and this type of comparison has been noted in the NMD literature as a technique patients use to cope with their disability (Krause-Bachand & Koopman, 2008; Mah et al., 2008; Nätterlund et al., 2001). However, one individual in this study felt guilty about posting when others were more severely affected by their conditions. This result mirrors findings from Sandaunet (2008), who found that some breast cancer OSG users felt guilty about being involved in the group as they were not as ill as others in the group. Therefore, the relationship between comparing oneself to others in an OSG and feeling more positive about

one's own condition may not always hold true. Given that the nature of the group was to support people with multiple NMDs who may all be at different stages in terms of illness progression, it is likely that comparisons are an inevitable, and unavoidable part of reading other members' stories.

Interestingly, comparisons between members in terms of non-disease aspects, such as political interests, were discussed by some interview participants when explaining their own personal engagement in the group. These results are interesting as they show the potentially broader influences that may impact on members' engagement with such groups other than, for example, satisfaction with informational or social support received. It seems that members use comparisons with others to situate their online experiences, thereby again highlighting the relational aspects of participation. Thus, members' online experiences were importantly defined by how they perceived others in the group in comparison to themselves.

Finally, the findings of the current study point towards the anonymity of the OSG setting as a potential limitation for the members. While Walther and Boyd (2002) suggest that the anonymity offered by the internet can heighten the ability of people to disclose information online, the experiences of certain individuals in the interview study suggest that this may not be the case for all participants, as some still had inherent concerns about the actual anonymity of participating in the group. This may be heightened by the fact that this particular online group was publicly accessible.

9.3 Methodological reflections

In this section, methodological considerations are discussed in terms of developing future research to build on the results of this thesis. As an exploratory study of one particular OSG, the results presented provide a useful and detailed insight into the role of online support for people with NMDs. However, it must be noted that this research is inherently tied in to the specific group dynamics of this particular U.K. based group. Further research could attempt to clarify whether other OSGs (e.g., those specifically set up by patients rather than charities) for these disorders function in similar ways in terms of communication patterns and topics, or

whether members' experiences are similar in terms of the context through which they chose to access the group, factors which influence their subsequent engagement with the group and any personal impact of participation.

This thesis adopted a triangulated methodological approach, in that more than one methodology was used to study the same phenomenon (Johnson, Onwuegbuzie & Turner, 2007). Triangulation allows the researcher to draw on the particular strengths of multiple methodological approaches to improve the overall validity of the study and gain a wider and deeper understanding of a particular phenomenon (Johnson & Onwuegbuzie, 2004). This research involved the use of two different methodologies to examine the potential supporting role of NMD OSGs. The relative merits of each of these approaches are described below, as well as the benefits of combining these methods to gain a more thorough understanding of the NMD OSG experience.

This thesis demonstrated the utility of the analysis of message postings to an OSG to examine how members used this group, especially in terms of the early stages of the group's development. The message posts provided rich textual narratives for the researcher to study online experiences. As a methodological approach, the thematic analysis of message postings allowed the researcher to directly observe the entirety of the publicly-accessible aspect of communications on the OSG. This allowed the researcher to access a broader set of participant narratives, including the perspectives of those who may not take part in participatory research (Seale et al., 2010), such as in the interview component of this thesis.

In contrast to survey methods of gathering information on online experiences where researchers' pre-conceived knowledge and theories inevitably shape the collection of data (Sweet, 2001), message postings provide researchers with rich sources of data which are free from the power issues inherent in participatory research methods, where the researcher is generally in control of proceedings. The message postings method used in this thesis allowed a certain level of bias to be reduced from this qualitative research, as the data collected were naturally occurring and thus researcher bias in the data collection phase was minimised (Malik & Coulson, 2008). The use of message posts data and the

inductive analysis approach meant that the study of members' online experiences was closely grounded in members' actual online activity.

While this type of communication is most useful in terms of understanding how people communicate online, it can provide limited information on outcomes of participation (Eysenbach, 2003) or indeed participant motivations or reasons for engagement. As mentioned in Chapter 4, such non-participatory methods are often best used in conjunction with other methods for a richer understanding of online experiences (Robinson, 2001).

The use of telephone interviews and IPA methodology allowed the researcher to examine participants' in-depth reflections and accounts of their online experiences. The particularly valuable aspect of this method was the ability of the researcher to probe interesting avenues of enquiry within participants' accounts of their online experience.

Other qualitative data collection methods were considered in this research process before deciding upon the use of telephone interviews. Online e-mail interviews were also considered as a potential method as they have been used previously by researchers examining sensitive health issues (Dale & Hunt, 2008; Hunt & McHale, 2007), with some authors suggesting that such methods may foster anonymity and increased participation in relation to research on sensitive issues (Mann & Stewart, 2000; Meho, 2006). Online interviews can be useful for those who are geographically distant or who have mobility difficulties (O'Connor & Madge, 2001). Other interviewing options available to researchers include synchronous online text-based interviews, often achieved through internet chat rooms or instant messaging facilities. Online surveys can also be used to garner qualitative data from OSG participants. Online surveys have a number of attractive features for researchers in terms of the ability to reduce geographical barriers to participation, reduce cost (Fricker & Schonlau, 2002), and reduce missing data (McCabe, Couper, Cranford & Boyd, 2002).

While online interviewing and survey methods may present a convenient way of accessing OSG participant experience, there are a number of reasons why telephone interviews were chosen in this research over these online methods. Previous research has suggested that online chat

interviews can provide less depth of information than traditional face-to-face interviews (Davis, Bolding, Hart, Sherr & Elford, 2004). Participants can also have difficulty using the necessary software (O'Connor & Madge, 2001). E-mail interviews can be particularly lengthy undertakings (Kivits, 2006) and it can be difficult to tell whether participants are still engaged in the process over time (Hunt & McHale, 2008; Seymour, 2001). While non text-based online interviewing options can also be facilitated by web-based voice and video formats, the use of video software also necessitates that participants have access to suitable technology, which can be limiting in terms of sampling (Hewson, 2007).

By using telephone rather than online interviewing or indeed qualitative survey methodology, it was also felt that the researcher could more readily access participants' spontaneous interpretations of their online experiences. It was felt that such online interview methods may have been overly burdensome for participants in this study in terms of the demands of writing. This was especially the case when the researcher reflected on her experiences of the difficulties encountered when attempting to collect survey-based data from this group of participants (see Appendix 4).

The telephone interviews allowed the researcher and participant to converse in a freely flowing conversational style and allowed the researcher to develop rapport easily, which may have facilitated participants' willingness to contribute and engage at length with the researcher's questioning. There is evidence to suggest that the quality of research interviews can be enhanced when the research allows for interviews to be carried out in the domestic context (Seymour, 1998). There is also evidence to suggest that female research participants have a preference for taking part in research in a home setting (Seymour, 1998; 2001). Given the all-female make-up of the interview sample, not to mention the potential obstacles faced by people with NMDs in attending face-to-face interviews, it is likely that the telephone interview method was particularly useful in garnering participant experiences and would be a useful tool in further research with this study population.

The methodologies used in this thesis provided the researcher with two different, but complementary lenses from which to explore the experience of online support group use in NMDs. The combination of methods

allowed for a more integrated understanding of the role of online support groups than either of the methodologies would have achieved in isolation.

The methodologies used complemented and integrated with each other in several ways. Examining the complete set of messages posted to the group over the first five months of the group's existence allowed the researcher to develop a broad, detailed overview of how this group was used by the whole membership of active users of the group. By using the naturally evolving conversation on the group message board as a data source, a comprehensive understanding of how members used the board was gained which was grounded in participants' own online narratives. While this methodology clarified how members used the board, it is inherently more difficult to examine other reflective aspects of their online experience using this methodology alone.

Leading on from the message posting analysis, there were numerous questions about participants' online experiences which remained to be addressed. The interview component of the study therefore helped to clarify the aspects of the online experience which were more difficult to extract from participants' online conversations, such as their motivations for participation, their reflections on their online experience and any impact of participation on their lives. The interactive methodology used in the IPA telephone interview component of the study allowed the researcher to examine these issues in more depth with a subset of users of the group, by encouraging participants to reflect on their online experience.

These two methodologies provided a combination of a broader overview, from the perspectives of all active users of the group, and a more nuanced, in-depth analysis of a smaller set of members' online experiences. Combining the methodologies ensured that there was significant breadth and depth to the analysis of members' online experiences and that a broader account of the online experience could be ascertained.

The research questions and qualitative methodologies used in this thesis allowed the researcher to build a qualitatively rich picture of: how members used an OSG in terms of how members communicate; the context through which members chose to use the group and their

subsequent experiences; and any personal impact of participation. In terms of future research, further triangulation of these methodologies could develop our current understanding of the potential role of OSGs in NMDs. As suggested by LaCoursiere (2001), a mixed method approach is likely to provide for a more integrated understanding of the role of OSGs for members.

The results of this thesis add to the evidence that online support can have beneficial effects on how people cope with health conditions (e.g., Gustafson et al., 2005, 2008). OSG support-seeking may be seen as an active approach to coping with having an NMD. As discussed in Chapter 2, active coping is often linked to better psychological outcomes (Taylor & Stanton, 2007). Future research could examine whether this particular active approach to coping is quantitatively linked to better psychological health outcomes among this population. In developing further research and further triangulating research approaches to understanding this phenomenon, quantitative, outcome-based studies could be considered which seek to examine whether participation in an OSG for NMDs can have any measurable beneficial impact on members' psychological well-being. The following section will outline some of the study designs which could be used in these studies, and some of the outcomes which could be assessed in future quantitative studies, as well as some of the potential difficulties in conducting such research.

Potential study designs which could be used in quantitative evaluations of the impact of OSG use include cross-sectional survey studies and longitudinal prospective studies or controlled studies. Cross-sectional quantitative studies could be useful to examine the extent to which participants may benefit from OSGs on a variety of outcomes measures. Such studies can also be used to examine the levels of benefits experienced by members in relation to their level of participation and to examine the associations between processes and outcomes of OSG participation (e.g., Mo & Coulson, 2012).

Cross-sectional studies, however, cannot be used to infer causality or the direction of causality of any impact of OSG use. Some authors argue that randomised controlled trials are needed to boost evidence on the efficacy of OSGs in improving patient outcomes (Eysenbach et al., 2004). However,

Barak, Grohol and Pector (2004) question the need for, and suitability of, RCTs as a method of assessing the impact of self-help groups online. As OSGs are generally naturally occurring, it would be difficult to replicate this experience in experimental settings. The findings from experimental studies may not generalise well to the various unique conditions of naturally occurring OSGs including participant motivations and the anonymity inherent in using a naturally occurring group.

Longitudinal prospective studies, while not allowing the same level of experimental control as an RCT, can allow researchers to investigate the effects of participation in an OSG over time on a range of outcome measures. In terms of evaluating quantifiable outcomes of participation, a number of outcomes may be relevant to the study of NMD OSGs. These outcomes are discussed in relation to the findings in the current study, in the context of the literature reviews presented in Chapters 2 and 3.

Some of the empowering outcomes and processes included in questionnaires developed by van Uden-Kraan et al. (2009) may be particularly relevant to assessing the potential benefits of participation. These outcomes include being better informed, having increased confidence in dealing with medical professionals, having increased involvement in illness management, experiencing increased optimism, experiencing greater perceived control, having improved social well-being and having higher self-esteem. In particular, improved social well-being and being better informed could be important outcomes due to the importance of social and informational benefits identified in both components of this thesis.

It remains to be seen whether participants could experience some of the other empowering outcomes included in van Uden-Kraan et al.'s (2009) empowering outcomes questionnaire. For example, it is difficult to know whether greater optimism and greater perceived control over illnesses can be gained through OSG participation in relation to conditions which are often progressive. These empowering outcomes may be more relevant to those suffering from chronic rather than progressive illnesses. The exchange of hints and tips on the message board in terms of coping suggest that participation may influence illness management, thus this could be a relevant empowering outcome for the group. Similarly, in the

results of the message postings analysis, it was seen that participants discussed ways of raising the profile of their condition in terms of dealing with health professionals and the general public. Thus, is it is possible that participants may experience the empowered outcome of increased confidence in dealing with their doctor. These speculations would need to be tested in further studies.

In terms of understanding any changes in participant outcomes, the empowering processes scale developed by van Uden-Kraan et al. (2009) could be particularly relevant in understanding why people may benefit from participation and thus could be used to examine any mediating or moderating effects of these processes on empowering outcomes. These processes include: exchanging information, encountering emotional support, finding recognition, helping others and sharing experiences. Building on the results of both the message posting analysis and the interview study in this thesis, it is likely that all these processes may be relevant to users of NMD support groups. Finding recognition may be particularly important due to the problems encountered by participants in having their condition recognised and their experience of feeling less isolated when meeting others who have their condition. A further avenue for quantitative research in this area would be to examine whether the 'finding recognition' process is a more common or important empowering process for those who use rare disease OSGs, in comparison to those who use OSGs for more common health problems, such as diabetes.

In previous research, the social support functions of OSGs have been well established, particularly in relation to the key role of informational support exchange, therefore social support remains likely to be a key outcome of interest in terms of assessing OSG participation. In future, perceived social support could be measured as an outcome using established social support measures such as the Medical Outcomes Study social support survey (Sherbourne & Stewart, 1991). The MOS is a 19-item social support survey, validated among patients with chronic health conditions, which measures the perceived availability of support along four functional aspects of social support: emotional/informational, tangible, affectionate, and positive social interaction. The sub-types of support in this particular scale (e.g., emotional/informational) map on well to the types of support often found to be present in OSG

communication through qualitative thematic/content analysis (e.g., Mo & Coulson, 2008; Coulson & Greenwood, 2012).

A further outcome which may be directly relevant to assessing the outcome of participation on this group is that of loneliness. Members discussed the isolating impact of living with rare NMDs and how the group was important in terms of realising others were in a similar situation and that they were not alone in their experience. Validated loneliness measures such as the UCLA loneliness scale (Russell, 1996), which is a well-known and widely used measure of loneliness which has been used in the OSG literature, could be used to examine the effects of OSG use on members' well-being.

In designing both cross-sectional and longitudinal studies, level of OSG use is also likely to be a key consideration which may be related to psychological outcomes. A growing body of research suggests that a higher frequency of usage (i.e., frequency of message posting) is related to greater benefit (Barak & Dolev-Cohen, 2006; Houston et al., 2002; Rodgers & Chen, 2005). However, some research suggests that lurkers may benefit in similar ways from using an OSG (Mo & Coulson, 2010; van Uden-Kraan, Drossaert, Taal, Seydel et al., 2008). Further work is needed to examine the differential experiences of lurkers and posters.

A limitation of this thesis is that only the experience of members who were actively involved in posting in the OSG were included in the research. This has previously been identified as a disadvantage of using message postings as a method of data collection (van Uden-Kraan, Drossaert, Taal, Lebrun et al., 2008). It was unfortunate that no lurkers volunteered to take part in the interview study. Previous research has examined the experiences of lurkers using survey methods (e.g., Mo & Coulson, 2010) so this may be a way forward in terms of understanding lurkers' experiences and comparing these experiences to those who actively use the group. For example, it would be helpful to identify whether the limitations mentioned by participants in the interview study may actually be barriers to participation to other potential users. Similarly, it is not known whether lurkers experience any particular advantages or disadvantages to not actively taking part in the group. Further research in this area of limitations or disadvantages to online

support group use can help those who provide and moderate OSGs to create the best possible online experiences for those using NMD and other health-related OSGs.

There are a number of issues which may need to be considered, however, in the design of online survey studies with this particular research population. The existing online support research is particularly scant in terms of longitudinal studies of naturally occurring online support groups. This may be due a number of methodological difficulties in conducting this type of research with naturally occurring OSGs. An overview of these issues is considered below, along with some practical suggestions for countering some of these problems. These reflections are based on the researcher's experience of testing the feasibility of collecting survey data in a pilot phase of this thesis process (see Appendix 4).

While large scale participatory studies would be useful to extend the findings of the current thesis, response rates to online research requests for surveys have tended to range from moderate to poor (Fricker & Schonlau, 2002), with research suggesting that internet surveys engender a lower response rate than postal questionnaires (Crawford, Cooper & Lamias, 2001; McDonald & Adam, 2003). This may be due to online communities seeing research invitations as unwanted postings or spam (Mendelson, 2007). Fricker and Schonlau (2002) suggest that this is a key challenge for online researchers in distinguishing their surveys from the plethora of commercial and advertising surveys which populate the web. Witte (2009) suggests that internet users can tire of research invitations due to their proliferation in peoples' online experiences, describing this phenomenon as 'survey fatigue'. It can also be difficult to gain moderators' consent or response to post study invitations (Im et al., 2007). Evidence for the effect of survey length on participant retention are mixed (Galesic & Bosnjak, 2009; Cook, Heath & Thompson, 2000).

Options for improving response rate and retention may need to be considered, such as offering incentives such as prize draws for participants who complete surveys. Similarly, researchers can work to highlight the relevance of their research to the online community membership (Wright, 2005). As discussed above, qualitative research can be particularly useful in determining the types of outcomes relevant for

quantitative survey-based research and such information could be used to ensure quantitative surveys are not overly lengthy to try and encourage retention of participants in online survey studies. As moderators are important individuals who help set and reinforce group norms, researchers could involve moderators in study designs to help improve recruitment and retention, however their endorsement may not mean that all members will be interested in the research (Cho & LaRose, 1999). Due to their intimate knowledge of the groups they moderate and their understanding of group dynamics, it is likely that moderators' feedback could prove useful in the piloting of the suitability of a research tool. They could also help with the promotion of the study to members of the OSG by posting study advertisements and ensuring these advertisements remain visible in online message boards.

All of the above mentioned strategies were employed in the pilot phase of this thesis (see Appendix 4) to improve recruitment rates to an online survey study. However, recruitment rates were still not satisfactory. After two attempts to conduct survey studies with this online group, at both the early stage of the group's development and a year after the initiation of the group, it was considered unethical to keep trying to collect this type of data from participants.

Conducting longitudinal studies may always be problematic, due to the fact that members can join and leave OSGs easily. Some members may only participate once to find information and leave, and maintaining their interest in a research study related to the group may be difficult. Thus, longitudinal studies may always be a challenging aspect of OSG evaluation research and the feasibility of collecting data in this manner should be assessed before developing large-scale prospective studies.

9.4 Clinical implications

This thesis suggests that OSGs can provide an important outlet for those affected by NMDs to gain support. This support, however, is not without its limitations. In terms of clinical practice, health professionals working with patients and carers, especially those newly diagnosed with these

disorders, could highlight the availability of such support to patients to help them realise they are not alone with their condition and to help them gain access to valuable experiential information.

Advancing academic work in this area can help to update clinicians' knowledge on the information and support needs of patients and carers affected by these conditions. Dissemination of research findings to professionals working in the area of NMDs can help raise awareness of how new peer online support opportunities are changing patient and carers' experiences of information and support in relation to these disorders. The message posting analysis component of this study has previously been presented at the BPS Health Psychology Conference 2011 and thus the dissemination of this work has begun. The researcher has considered destination journals for journal articles resulting from this thesis including 'Neuromuscular Disorders' and 'CyberPsychology and Behavior'.

An area that this study did not focus on was the reliability of information found on such online groups. Concerns about the quality of OSG information previously identified in the literature (e.g., Esquivel et al., 2006) were not mentioned by participants. The message posting analysis suggested that members were cautious to highlight the bounds of their knowledge in terms of symptoms/diagnosis information and suggested members seek professional advice when in doubt regarding any illness experiences.

This study did not test the accuracy of the medical information provided or specifically ask members to comment about the perceived accuracy of information exchanged. This is an area which could be examined by clinicians in order to assess the validity of medical information shared. However, it must be noted that in this research the exchange of experiential information was particularly prominent and valued. Thus, accuracy of medical information may not be a key measure of the success of such a group, as it was the peer experiential information exchange that was valued. Members were careful to direct others to seek professional advice with medical problems that were mentioned, as necessary.

Certain limitations of online support were identified in this thesis, in particular in terms of the OSG not being able to fully provide for the needs

of members, difficulties relating to others on the group, technological issues, and privacy issues. However, participants' experiences of using online support were primarily positive. The researcher did not witness any evidence of abusive behaviour on the online support group, nor did the participants report any such negative experiences. This, however, does not mean that other members did not experience any detrimental effects of participating. The nature of the sample in the interview study, in that all users were still active users of the forum, means that it is difficult to tell whether their experiences would represent the wider experiences of both lurkers on the group and those who may have stopped using the group over time. It was also not possible to ascertain why certain people with NMDs and carers use this online support group and others do not.

There are also some unique features of the current group that may mitigate some of the potential negative aspects of online support group use. In both empirical aspects of the study, it was evident that there were clear ways in which members, especially the group moderator, made efforts to welcome and offer support to others to create a friendly, welcoming enviroment. The group moderator was therefore potentially very important in creating and maintaining this positive atmosphere and their influence on the success of the OSG should not be underestimated. This is an important clinical implication for professionals or lay people setting up online groups, in terms of the importance of having adequate moderation of forums and support for moderators in their pivotal role.

The fact that this support group was run by a charitable organisation which interviewed and selected moderators for this job could also help to explain why the group maintained this positive and welcoming atmosphere. This could potentially have a further protective impact against disinhibited negative online behaviours in the group. In summary, it is important to recognise that this study focused on one particular OSG set up by a charitable organisation with multiple moderators. It may be that some of these factors were influential in creating a positive experience for members and therefore members' experiences of unmoderated or peer-run OSGs may be different to the experiences reported here. It is therefore impossible to say whether OSG use would definitely be a positive experience for all those affected by NMDs across all types of OSGs.

9.5 Conclusions

This study provided a novel, valuable insight into how people used a new OSG for NMDs. This included how they established a sense of community to support one another with NMD issues, especially in relation to practical and emotional aspects of diagnosis, as well as interpreting and managing symptoms. The board was also used as a platform for discussion of the societal and political issues which affected members' experiences of dealing with an NMD and to discuss and endorse activities which raise awareness of these types of rare conditions. Members valued the connection to similar others in a friendly, social environment and valued the opportunity to help others by passing on their experience. However, members also noted limits of online support, in terms of fully meeting the needs of those affected by NMDs.

This was a qualitative exploratory study based on one particular online support group. The strengths of this study lie in the in-depth qualitative approach to understanding participant experiences. Further empirical work is needed in order to clarify the generalisability of these findings and to clarify the outcomes of participation in this type of group across a wider range of users of NMD OSGs, including carers and those who lurk rather than post on such groups.

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Appendices

Appendix 1 – Ethical approval letter for message posting analysis

Institute of Work, Health & Organisations
http://www.nottingham.ac.uk/iwho

The University of Nottingham

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16/09/2010

Dear Oonagh

I-WHO Ethics Committee Review

Thank you for submitting your proposal on "An investigation into the psychosocial impact of online support group participation for people with neuromuscular disease and family carers". This proposal has now been reviewed by I-WHO's Ethics Committee to the extent that it is described in your submission.

I am happy to tell you that the Committee has found no problems with your proposal. If there are any significant changes or developments in the methods, treatment of data or debriefing of participants, then you are obliged to seek further ethical approval for these changes.

We would remind all researchers of their ethical responsibilities to research participants. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society. If you have any concerns whatsoever during the conduct of your research then you should consult those Codes of Practice and contact the Ethics Committee.

You should also take note of issues relating to safety. Some information can be found in the Safety Office pages of the University web site. Particularly relevant may be:
The *Safety Handbook*, which deal with working away from the University.
http://www.nottingham.ac.uk/safety/
Safety circulars: Fieldwork P5/99A on
http://www.nottingham.ac.uk/safety/publications/circulars/fieldwk.html
Overseas travel/work P4/97A on http://www.nottingham.ac.uk/safety/publications/circulars/overseas.html
Risk assessment on http://www.nottingham.ac.uk/safety/publications/circulars/risk-assessment.html

Responsibility for compliance with the University Data Protection Policy and Guidance lies with all researchers.

Ethics Committee approval does not alter, replace or remove those responsibilities, nor does it certify that they have been met.

We would remind all researchers of their responsibilities:
- to provide feedback to participants and participant organisations whenever appropriate, and
- to publish research for which ethical approval is given in appropriate academic and professional journals.

Yours sincerely

Professor Nadina Lincoln
Chair IWHO Ethics Committee

Appendix 2 – Message posting analysis thematic map

Theme 1: Connecting and Sharing.

    Establishing common ground
        Disclosing personal information
        Connecting with similar others
        "Make yourself at home"
        Sharing aspirations for community development
    Sharing diagnosis experiences
        Introducing relationship to NMDs
        Diagnostic delay
        Sharing negative emotional reactions to diagnosis
        Sharing relief at eventual diagnosis
    Sharing diagnosis support
        Validating members' experiences
        Validating members' emotions
        Comforting and supporting members
        Signposting to support and information sources

Theme 2: An Understanding Audience.

    Collective symptom interpretation
        Sharing symptoms
        "Does anyone else feel this way?"
        Sharing knowledge/experience of similar symptoms
        Encouraging medical advice seeking
    Emotional reactions to progressive symptoms
        Anxiety about symptoms
        Regret at declining functional ability
        Feeling unsupported in the medical management of
        symptoms
        Reluctance to use aids/adaptations
        Maintaining a positive outlook
        Valuing support from close friends and family
    Supporting one another with condition management
        Sharing information
        Validating feelings regarding symptoms
        Reassuring members of available mutual support
        Encouraging a positive outlook

Theme 3: Recognition and Awareness.

Sharing difficulties regarding NMD recognition
  Facing poor professional understanding
  Contending with public misconceptions
  Feeling misrepresented by government and media
Fostering discussion on political, societal and healthcare issues
  Have you heard?
  Sharing concerns and hopes regarding political change
Raising awareness
  Raising awareness through educating others
  Raising awareness through campaigning
  Valuing volunteer and charity support in championing issues
  Valuing research in terms of hopes for the future

Appendix 3 – Interview schedule

<u>Introduction</u>
- Introduce interview topics
- Ask member to confirm personal details (date of birth/diagnosis)

<u>Dealing with neuromuscular disorders (NMD)</u>
- Can you discuss any positive or negative impact having an NMD has on your daily life? (e.g. on your personal/social/working life?
- In terms of dealing with NMD, what do you think are your support needs, if any?
- In terms of dealing with your condition, who or where do you get support from? (besides OSG name)?
- Please discuss how helpful (or unhelpful) you find these different types of support in dealing with your condition.
- Are there any support opportunities available to you that you don't use? If so, can you describe why you don't access these types of support.

<u>Previous use of Online Support Groups (OSGs)</u>
- Prior to using, can you describe any use of other OSGs in relation to MD that you had?

    Prompts (if member has prior experience):
    - ➤ What other OSG(s) have you used?
    - ➤ Please describe when you first accessed such an OSG.
    - ➤ Did you have any particular reason for accessing an OSG(s)?
    - ➤ Can you remember how you found out about these group(s)?
    - ➤ Did you join the group? Can you remember your reasons for doing so? If not, did you have any reason for not joining?
    - ➤ How did you use this OSG(s) (e.g. to post/reading/Private messaging)
    - ➤ Can you describe any helpful aspects of using the group(s) that you experienced?
    - ➤ Can you describe any unhelpful aspects of using the group(s) that you experienced?
    - ➤ Can you please describe how long you used the group for?
    - ➤ Are you still using this group(s)?

- ➢ What factors influenced your decision to stay in this group/leave this group(s)?
- ➢ Do you think your experience of using other OSG(s) influenced your decision to use (OSG name)? Please discuss your reasons.

Prompts (If member does not have prior experience):
- ➢ Were you aware of any other OSGs in relation to your condition before finding out about (OSG name)?
- ➢ If yes, did you have any particular reasons why you hadn't tried any other OSG related to MD before?

Deciding to use (OSG name)

- Can you describe how you found out about (OSG name) OSG initially?
- What was your initial reaction to finding out about the group? (Did you think it was something that might be of interest to you or not?
- Can you tell me about your reasons for joining the group? (e.g. any expected benefits/information/support you hoped to gain?)
- When you joined the group, did you have any concerns about using the group? (Any reservations/any disadvantages?)
- Did you join the group as soon as you could or did you wait a while before joining?
- If you waited for a while before joining what encouraged you to join when you did?

Using (OSG name):

Reading posts:
- When you first started to access (OSG name), were there any particular types of discussion threads or topics that you were most interested in reading?
- Over the entire time that you have used (OSG name) are there any types of discussion threads that you have found more or less interesting to you than others?
- Are there any topics related to living with MD that you would like to see on the forum that have currently not been discussed?
- Are you still accessing the forum to read postings?
  If yes:
  - ➢ Over the period of time that you have been accessing the forum to read postings, have there been any changes to the amount of time you spend reading postings on the discussion board?

> If you have experienced changes to how much time you spend reading postings, can you describe any reasons for this?

If you have stopped reading postings on the discussion board:
> Are there any reasons why you have stopped reading messages on the forum?

Posting messages:
- Did you ever post a message on the discussion board?
  If yes,
  > Can you tell me about your first post?
    Prompts:
    - Was it a post introducing yourself or a reply to someone else?
    - What type of information did you share and or/request?
    - When was it (shortly after or a long time after joining)?

  > How did you feel after posting for the first time?
    Prompts:
    - How did you feel about any responses you got to your first message?
    - Did you feel encouraged/discouraged to keep posting?

  > Did you continue to post messages to the discussion board after this first message?
    If yes,
    - Can you describe what types of topics you have posted about in on the discussion board? (Any particular topics you requested information/support about or tended to reply about?)
    - How did you feel about the responses you received from others?
    - Can you describe any advantages you experienced from posting messages on the board?
    - Can you describe any disadvantages you have experienced of posting on the board?
    - Has anything changed about the amount/types of posts you contribute? Can you tell me what has influenced this change?

If not,

- Are there are any reasons why you have stopped posting?

If you have never posted to the discussion board,

- Can you please describe any reasons you have for not posting to the discussion board, or any barriers you experience to using it?

Private messaging (PM)

- Have you ever been involved in a private conversation with another member via PM?

  If yes,

  - Can you remember your reasons for doing so? (e.g. did you have a specific question(s) to ask a member, did someone contact you initially?)
  - If you have used both the discussion board for posting and the PM function:
    - Can you describe any similarities or differences between the topics that you have discussed on PM compared to any topics you have discussed on the discussion board?
    - If you have used PM but not posted to the discussion board, can you describe why you preferred to use this method to contact members?
  - Are there any helpful aspects of using PMs that you have experienced?
  - Have you experienced any unhelpful aspects of using PMs?
  - Do you continue to use PMs?
    - If so, has there been any changes to the amount/types of PMs you send since you began using this function. Can you tell me about what has influenced this change?
    - If not, are there any reasons why you have discontinued using PMs?
  - Following private messaging, have you ever contacted any members offline? How did you find this?

  If you have never used PMs:

  - Please describe any reasons you have for not using this method of contacting members.

Overall Appraisal of accessing (group name):

- Looking back on your experience of accessing (OSG name), are there any personal benefits you have experienced from using the group?
- Have you experienced any disadvantages to using the group?
- Do you feel that your initial expectations of using the group have been met?
- How has your experience of using (OSG name) compared to your use (if any) of other OSGs for muscle disease?
- If you had concerns about using the group initially, how do you feel about these now?
- Do you feel using (OSG name) has had any impact on your relationship with other people outside of (OSG name) (e.g. family/friends)? If so, can you tell me about this?
- If you no longer access the group, can you describe your reasons?
- Please discuss whether you intend to continue using the group.

Appendix 4 – Pilot work description

At the beginning of the thesis process, the researcher tested the feasibility of collecting survey data from users of the OSG under study. An attempt was made to collect longitudinal data from the beginning of the OSG's development, using a web-based quantitative survey. The researcher felt that, as the OSG had recently been launched, it would be an opportune moment to test the feasibility of collecting longitudinal data to quantitatively assess outcomes of participation. Also, the literature on OSG group use is particularly scant in terms of longitudinal outcome studies (Eysenbach et al., 2004)

The researcher contacted the administrator of the online group to ask for permission to post a link to the survey on the message board of the OSG. The administrator also sent the survey to the charity research team for approval. After gaining permission to post the survey, the researcher was encouraged to become a member of the OSG in order to post the invitation to the online survey.

The survey collected demographic information, as well as information on reasons for OSG use, levels of OGS use and a range of well-validated, reliable outcome measures. The choice of these measures was informed by the literature on the psychosocial impact of NMDs presented in Chapter 2 and the emerging literature and theory on the processes and outcomes of OSG participation presented in Chapter 3.

Perceived social support was measured using the Medical Outcomes Study social support survey (Sherbourne & Stewart, 1991). The sub-types of support in this particular scale (e.g., emotional/informational) are well-aligned with the types of support often found to be present in OSG communication through qualitative thematic or content analyses. Perceived loneliness was examined using the UCLA loneliness scale (Russell, 1996).

Participants were also asked to complete a measure developed by van Uden-Kraan et al. (2009), which was specifically related to empowerment in OSG use. This measure asked participants to rate how frequently they experienced a number of empowering processes and outcomes while using the OSG.

Psychological well-being was measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), the Perceived Stress Scale 10-item (Cohen & Williamson, 1988) and the Self-Esteem Scale (Rosenberg, 1969). Caregiver burden was examined using the Zarit Burden Inventory (Zarit, Reever & Bach-Peterson, 1980). Coping responses were assessed using the Brief Cope (Carver, 1997)

In designing this study, it was hoped to statistically assess any changes in psychological outcomes (depression, anxiety, stress, loneliness, perceived social support, and empowerment) across three time points (baseline, 3 months, and 6 months, respectively) and to test for any moderating effects of level of OSG use, perceived social support, and coping responses on any changes identified.

The number of participants recruited to the study was low, despite the fact that the online survey remained open for seven months. Several study reminders were posted to the OSG message board and participants were offered the opportunity to enter a prize draw for vouchers for use on www.amazon.co.uk. Only 19 participants completed the baseline survey. Fifteen of these participants gave their permission to be contacted for 3 month and 6 month follow-up surveys. However, only 12 participants completed the survey at time-point two, and this decreased to 10 participants at time-point 3. It was therefore not feasible to conduct inferential statistics on the data that were available.

A further attempt was made to conduct a cross-sectional mixed methods study approximately one year after the original longitudinal survey was posted. This study was designed to examine the relationship between levels of OSG use and a range of psychosocial outcomes, as well as to examine the levels of empowering processes and outcomes experienced by members. It was felt that, at this stage, more participants may have joined the group so it may have been more feasible to collect survey responses. The number of registered users to the group had grown to 3636. However, only 498 users had posted at least one message.

In this questionnaire, a number of the psychological measures used previously in the longitudinal study were retained. Some outcomes were omitted to reduce respondent burden (i.e., the Brief COPE and the Self-Esteem Scale). A short number of open-ended questions were also included to access participants' reasons for using the group, their satisfaction with their online experience, any impact of OSG use on coping and any perceived similarities and differences between the support available through the OSG and any other support they received or used in dealing with NMDs.

Permission was gained from the OSG moderator to post the link to this online survey. The link to the survey remained open for a second period of 7 months. Two reminders were posted to the board to ask people to consider participating. In order to help promote the survey among OSG members, the moderator also made the survey post a 'sticky' post, so that it was highly visible during the study recruitment period. The researcher offered a prize draw for participants to have a chance of winning vouchers for www.amazon.co.uk and posted several study reminders. Despite these efforts to promote the survey, only 16 responses were gained. Thus, it was not possible to conduct inferential statistics on this data. The qualitative

data, while interesting, were minimal, often only containing one to two line responses.

After attempting to gain quantitative and qualitative data using survey methods, it became clear that this method would not be the most useful in terms of illuminating the experiences of members using this OSG. Building on the interesting but limited amount of qualitative data which emerged in the second survey, it was decided to employ semi-structured telephone interviews to more fully access the experiences of members. It was felt that by accessing participants' experiences in this way, a more in-depth and meaningful exploration of participant experiences could be gained, whilst negating any potential burden associated with online survey methods.

Appendix 5 – Interview invitation e-mail

Dear Sir/Madam,

Re: (group name) study

Hope you are well. I am contacting you regarding a (OSG name) survey study which you participated in. You indicated that you may be interested in taking part in a follow-up part of this study.

I am now contacting you to ask whether you would be interested in taking part in a phone interview to discuss your experience of using or deciding not to use (group name) over the past year. Interviews are expected to last between 30 and 45 minutes. You are free to take part in these interviews irrespective of whether you continue to use (group name) or not. Similarly, it doesn't matter whether or not you filled in any follow-up questionnaires. You are welcome to take part.

Participation in the phone interview will be entirely anonymous and confidential and your participation is entirely voluntary. Should you decide to take part in the interview, you can choose to stop the interview at any time and if you would like to withdraw your data, you can contact me after your interview.

If you would prefer not to take part, please feel free to ignore this e-mail. If you would like to know more about the interviews or you would like to get in touch to discuss taking part, please reply to this e-mail and we can discuss the interview further and arrange a suitable interview date and time for you if you wish.

Thank you for your time.
Kind regards,

Oonagh Meade
Principal Researcher
E-mail: lwxom2@nottingham.ac.uk
Tel: 0115 8230541

Research Supervisors:
Dr. Heather Buchanan
E-mail: heather.buchanan@nottingham.ac.uk   Tel: 0115 846 7520

Dr. Neil Coulson
E-mail: neil.coulson@nottingham.ac.uk   Tel: 0115 846 6642

Appendix 6 – Study advertisement message post

Research Invitation

Dear member,

My name is Oonagh Meade and I am a PhD student at the Institute of Work, Health and Organisations at the University of Nottingham. As part of my research I am conducting a study which is exploring member experiences of using (group name). You may have previously completed a survey as part of this project.

I am now inviting members to take part in a phone interview to discuss their experiences further. If you would be interested in taking part in this part of the study, please contact me and I will send you a study invite with more information about what the study involves and how to take part.

Ethical approval for this study has been gained from the ethics committee at the Institute of Work, Health and Organisations at the University of Nottingham.

Thank you for taking the time to read this invitation. Please contact me at lwxom2@nottingham.ac.uk if you require further information.

Best wishes,

Oonagh Meade

E-mail: lwxom2@nottingham.ac.uk
Tel: 0115 8230541

Exploring members' experiences of using (group name)

Participant Information

You are invited to participate in a follow-up telephone interview as part of the research study you have previously taken part in by completing a survey. The aim of this study is to examine the effects of (OSG name) participation for both adults affected by muscle disease and family carers who look after someone affected by muscle disease. A reminder of the study details are given in the information sheet below.

Study Description:
The primary purpose of this research is to explore members' experiences of accessing (OSG name) in relation to their emotional well-being. This study will therefore examine the potential benefits and drawbacks for members of using (OSG name) and will provide members with an opportunity to give feedback on their experience of using this online support group.

Study Procedure:
Participating in this part of the study involves taking part in a telephone interview which will last approximately 30 to 60 minutes. If you provide consent, your interview will be recorded. The questions you will be asked relate to your experience of deciding to use (OSG name) initially, your experience of using or not using (OSG name) and your future plans in relation to using (OSG name).

If you would like to participate in a telephone interview please complete the consent form which is available when you click on the "next" button at the end of this webpage.

Anonymity and confidentiality:
Any information you give will be collected in a secure and confidential manner. All recorded information will be kept in a password protected electronic format which only the research team will have access to. If any of your responses are used in any write-up of the project or academic papers, your anonymity will be preserved by removing any information which may identify you.

Withdrawal from the study:
While your participation in this study would be much appreciated, it is entirely voluntary. You are under no obligation to take part in this interview. If you do decide to take part you can end the interview at any time without consequence by asking the researcher to stop the interview

at any stage. You may also skip any questions which you are not comfortable answering. If after completing the interview you wish to withdraw your responses, you can e-mail the researcher and your interview responses will be removed from the study.

Should you have any further queries about this study, please do not hesitate to contact me at lwxom2@nottingham.ac.uk. If there are any issues which you would like to discuss relating to muscle disease, please contact the (charity name) using the contact details below:

[Charity contact details omitted]

Your interest in this research is much appreciated,

Oonagh Meade
Principal Researcher
E-mail: *lwxom2@nottingham.ac.uk* Tel: 0115 8230541

Research Supervisors:
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Exploring members experience of using (group name)

<u>Participant Consent Form</u>

Please read the following statements carefully:

- I voluntarily agree to take part in this study.
- I have read and understood the participant information on the previous page.
- I am willing to have my telephone interview recorded by the researcher.
- I understand that I have the right to skip any questions and to withdraw from the study during the interview without consequence.
- I understand that I have a right to withdraw from this study after completing the interview without consequence by e-mailing the researcher and asking for my responses to be removed.
- I understand that any information recorded about me will be kept in a secure database.
- I understand that only the researchers will have access to my responses.
- I agree that information or quotes from my responses can be used in any reports on this project. However I understand that any information which could identify me will be removed.
- I understand that this research has received ethical approval from the ethics committee at the Institute of Work, Health and Organisations at the University of Nottingham.

1. Please provide your date of birth (to verify participant identity):

2. I have read and understood the participant information sheet and consent form. By clicking on the 'continue' button below I am voluntarily giving my consent to take part in this study.

Continue

Appendix 9 – Ethical approval letter for interviews

Institute of Work, Health & Organisations
http://www.nottingham.ac.uk/iwho

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

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09/05/2012

Dear Oonagh

I-WHO Ethics Committee Review

Thank you for submitting your amendment to your study entitled "An investigation into the psychosocial impact of online support group participation for people with neuromuscular disease and family carers". This amendment has now been reviewed by I-WHO's Ethics Committee to the extent that it is described in your submission.

The Committee has accepted your proposed changes. If there are any further significant changes or developments in the methods, treatment of data or debriefing of participants, then you are obliged to seek further ethical approval for these changes.

We would remind all researchers of their ethical responsibilities to research participants. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society. If you have any concerns whatsoever during the conduct of your research then you should consult those Codes of Practice and contact the Ethics Committee.

Responsibility for compliance with the University Data Protection Policy and Guidance lies with all researchers.

Ethics Committee approval does not alter, replace or remove those responsibilities, nor does it certify that they have been met.

Yours sincerely

pp Wadham

Professor Nadina Lincoln
Chair IWHO Ethics Committee

Appendix 10a – Interview coding sample, interview 1

Open Coding	Raw Interview Data	Emergent Themes
Sees self as stoic, perception of stoicism as a way of coping. Providing example of stoic approach to coping with illness. Short, curt sentences. Repetition of 'I'. Wanted to be left alone when ill. Repeatedly reinforcing idea of shutting people out, wanting to deal with illness on own. Having somebody to help can be a negative. 'They're on at me' - Gets annoyed by people trying to help. Repetition of questions - highlighting annoyance with people trying to help. Preference to cope on own with illness. 'Get through' – illness is to be gotten through, a journey. Noting that an independent coping style may be excessive – *'It's a little bit much'* Joking about high level of telephone contact with friend Usefulness of friend being uninvolved Contrasting friend with family member –'not t[h]ere all the time' – benefit. Lack of closeness has value. Finds friend's 'degree of separation' from daily life to be useful for chatting and sharing ideas.	A: than the more modern-day sit down with someone talk it all out I: Yeah A: and this. So 'em but fairly stoic and it's like classic example is being ill with a cold. I: Yeah A: I locked my door. I shut my curtains. I went to bed and that was as much interaction as I wanted with anybody for two or three days. I: Yeah A: I'm not one in fact it annoys me if I've got somebody here and they're on at me for you know do I want this? Do I want that? Do I need this? I: Yeah A: I'd rather they go away and be left alone and I'll get through. I: Yeah A: So it's a little bit much but I mean I know that I'm that way. But I do have a good friend that I will eh talk to. I: Yeah A: I think we we've contribute to B.T.'s profits I: [laughs] A: regularly throughout the year [laugh]. Because she is an uninvolved person. Because she's not a family member and she's not here all the time. I: Yeah A: she's got that degree of separation to be able to speak to and just bounce ideas with.	Findings ways of coping. Difficulty sharing issues. Coping by shutting others out. Others as source of stress. Difficulty relating to others. Illness as own, not a shared journey. Uninvolved person can be more understanding audience. An understanding audience.

Appendix 10b – Interview coding sample, interview 3

Open Coding	Raw Interview Data	Emergent Themes
Does not want to focus only on disability. Feeling that own experience is less valuable in light of others' experience. 'put up with' metaphor - As though carrying a burden. Not wanting disability to be sole discussion point. Talking to somebody with same illness is motivator to join OSG. Rarity of illness amplifies this. Rarity of illness means communicating on OSG is more valued. Especially before diagnosis. Illness might be imagined Illness may not be real Finding solace in shared experience. Validating the otherwise unreal.	C: Well, the thing is I mean I don't want to be talking about disability all the time. I: Yeah (.) So you don't want to kind of join too many (.) of those groups or? C: Well, no because I mean when I go on to (group name) I almost feel like a fraud because some of the people on there are a lot worse off than me. I: Ok. C: What have I got to complain about when they've got so much more to put up with? (.) Do you know what I mean? I: Yeah C: So I thought well I don't want to get, I don't want to be talking disability all the time. I: Yeah, I know what you mean. And say when you did join ah like the previous version of the group……did you have any particular reasons for joining that or like how did you hear about it in the first place…… C: I can't really remember how I heard about it [but] I suppose it was because I didn't know anybody else who had MD. C: You know because it's rare I: Yeah C: you know, you just don't know people that's got it. To be able to talk to somebody who has got exactly what you've got is you think wow it's not just me then because I mean some of the symptoms I mean probably especially in the early days were very you'd like oh, that's a bit odd you know it's just like oh, it just might be in my head or something like that you know. Oh I can't walk up these stairs without holding on that seems a bit odd. I: Yeah C: You think oh, no, no it's just me being stupid sort of thing. I: Did you kind of doubt some of those things in the first place? C: Yeah, yeah and then you find somebody else who says exactly the same you think wow there is something then it's not just me.	Not wanting to become the disability. Understanding illness in relative terms. Searching for common experiences. Not wanting to become the disability. Searching for common experiences. Searching for common experiences. 'It's not just me' Illness subject to perception. An understanding audience. 'It's not just me'

Appendix 10c – Interview coding sample, interview 6

Open Coding	Raw Interview Data	Emergent Themes
Intending to take part more than actually does. Time constraining use. 'Guarded' – Information online must be safeguarded. Careful about what puts online. Personal issues are guarded. 'Fear' of being identified at work. Example of problem at work – access.	F:I mean quite often I I I've got I'll read something and I'll intend to comment and I just don't get around to it I mean I I always intend to use it a lot more than I do and it's just it's just a matter of em time and em sort of also I'm sometimes a bit guarded about what I say on forums because you're never quite sure who might read your answers you know what I mean you might be so I'm quite careful about what I might if there was any sort of particularly personal issue or something I probably wouldn't use it em for fear of em......I was just thinking of an example for those who had a particular issue at work and they asked a question about it you know if if they had a real problem of access or something	Time constraining OSG use. Privacy concerns impacting engagement. Privacy concerns impacting engagement. Life online impacting life offline.
Aware of visibility online. Linking life offline with life online. 'MD lady' – illness as identity. Being identified by online activities in unintended context (work).	I: yeah F: and they someone at work who had the problem he was dealing with the problem maybe googled it and see Muscular Dystrophy lady can't use stairs at work and my thoughts what I'd been putting on the forum sort of came up as a result of their search and also other people didn't know it was me if you know what I mean because I'd had that problem that day I: yeah I know what you mean	Privacy concerns impacting engagement. Life online impacting life offline.
Not wanting world of work and OSG world to mix but aware that Internet allows this. Would value more privacy on OSG - 'closed'	F: and then if I I I had been talking about maybe really personal issues to do with my condition I wouldn't really want someone to have access to that I: do you think if the group was kind of more private like in terms F: I often thought that because if there were like maybe just a members only closed I: kind of part of it	Privacy concerns impacting engagement. Privacy could be improved.
Seeing potential difficulties with increased privacy	F: topic or something I mean other than the general ones that you find but em I suppose then it's difficult to to become a member I I don't know…	Technology inhibiting privacy needs.

Appendix 11 – Master table of interview themes

Themes	Participants					
	A	B	C	D	E	F
A valued connection to similar others						
'It's not just me'	Yes	Yes	Yes	Yes	Yes	Yes
Searching for common experiences	Yes	Yes	Yes	Yes	Yes	Yes
An understanding audience	Yes	Yes	Yes	Yes	Yes	Yes
Learning more relevant tips for coping	Yes	Yes	Yes	Yes	Yes	Yes
Increasing awareness collectively	Yes	Yes	No	Yes	Yes	No
A welcoming, social space						
Feeling welcome	Yes	Yes	No	No	Yes	Yes
A place for interacting 'with the person, not just the condition'	Yes	Yes	Yes	Yes	Yes	No
Non-pressured 'coffee shop style' atmosphere	Yes	No	No	Yes	Yes	Yes
Gratifying experience of helping others						
Why not share what you know?	Yes	Yes	No	No	Yes	Yes
Feeling useful	Yes	Yes	No	No	Yes	No
A support source with limits						
'They can just tell me their experiences but that's kind of it'	No	Yes	No	Yes	Yes	No
Privacy concerns impacting engagement	No	No	No	Yes	Yes	Yes
Difficulty navigating board	No	No	Yes	Yes	No	Yes
Difficulty relating to others	No	No	Yes	Yes	Yes	Yes

A = Alicia
B = Bernie
C = Carol
D = Donna
E = Elizabeth
F = Frances

Yes = sub-theme present in respective interview
No = sub-theme not present in respective interview