



**Experiences of attendance at a Neuromuscular Centre:
Perceptions of adults with neuromuscular disorders**

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Experiences of attendance at a Neuromuscular Centre: Perceptions of adults with neuromuscular disorders.

Abstract

Purpose

The aim of this research is to gain an insight into adults with neuromuscular disorders' experiences of attendance at a specialised, voluntary sector, Neuromuscular Centre and explore its value to these adults who attend for treatment, education or employment.

Method

This study was qualitative in design. In-depth interviews were conducted with 9 self-selected participants, recruited from the population of adults with neuromuscular disorders who attended the Neuromuscular Centre. Interviews were transcribed verbatim and thematically analysed. Thematic networks were utilised to aid interpretation.

Results

Participants saw the benefit of specialist input to remain mobile and independent for longer. The Centre created a culture of understanding and empathy which facilitated mutual support and self- acceptance. Opportunities for employment and education offered a sense of purpose. Sharing experiences developed self-knowledge and the ability to self-manage their condition.

Conclusion

Attendance at this voluntary sector Neuromuscular Centre provided physical, psychosocial and economic benefits. The Neuromuscular Centre through its holistic approach offers a unique model for rehabilitation of adults with neuromuscular disorders. As an enterprise, satellite centres adopting the ethos of the Centre could be created, which could potentially help to redress the inequalities in health care for adults with neuromuscular disorders.

Key words

Neuromuscular disease, long term conditions, rehabilitation, disability

Introduction

Muscular dystrophy and other genetically transmitted neuromuscular disorders (NMD) form a group of conditions which are characterised by progressive wasting and weakness of the muscles [1-5]. There are more than 30 different types of muscular dystrophy (MD), with over 70 000 people in Western Europe and 40 000 in the USA severely affected by the condition [5]. In the UK there are between 13 485 and 22 750 adults with NMD with severe symptoms [6], with a reported prevalence of 37.0/100 000 with inherited muscle disease in Northern England (7). It has been suggested, however, that there are around 60 000 people in the UK living with some form of the neuromuscular condition [8]. Although improvements in medical management have led to people with advanced NMD living well into adulthood, there is still no cure and some will continue to have long term disability and reduced life quality [9-11].

Given the challenges faced by people with NMD, it would seem reasonable for these individuals to expect a health and social care service, which supports their needs, to be readily available. However it appears that this expectation is often not realised. In the UK, inconsistency and insufficiency of service provision has been identified for adults with NMD [6, 8]. It seems that a deficiency in specialist care has resulted in individuals in a number of regions travelling to other areas to access clinics, or receiving no provision at all. In some cases, a shortage of specialist therapists has led to NMD clinics providing no access to physiotherapists with expertise in the condition, or any ongoing treatment [6, 8]. Concerns such as lack of support for adults with NMD to assist them to engage in work or access further and higher education have also been recognised [8].

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3 As a result of these findings, the need for a co-ordinated strategy to address the
4 issue of service provision for 'complex and rare diseases' has been highlighted [6]
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6 with recommendations for the development of guidelines, to improve standards of
7
8 health care for individuals with NMD [8]
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13 The pre 2010 UK government's stated priority was to enhance standards of care for
14 people with chronic disabilities. Through their National Service Framework (NSF) for
15 long term diseases [12], the previous government declared its commitment to
16 renovating health and social care services, with the aim of improving the quality of life
17 for people with chronic conditions. The main components of this policy included
18 prompt access to specialist healthcare, a workforce which can provide the necessary
19 expertise and skills, vocational rehabilitation and educational opportunities [12].
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23 Although as a result of the recent elections a new government is now in post, at the
24 time of writing, no changes to this policy have been announced.
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27
28 In order to ensure quality provision of service for people with NMD it would therefore
29 seem essential to offer specialist health interventions that are known to be most
30 beneficial for these individuals. However there is a paucity of research regarding
31 rehabilitation of adults with neuromuscular disorders, leading to a lack of knowledge
32 of how service provision can be optimised for this client group [6]. Most studies
33 undertaken have been quantitative in nature, concerning exercise therapy, with
34 inconclusive evidence as to the most favourable regime [13]. Multi-specialist
35 intervention has been promoted but there is no agreement as to the best approach
36 [8,14,15] or the most appropriate duration of allied health intervention [16,17]. A
37 study evaluating the impact of multidisciplinary rehabilitation for adults with muscular
38 dystrophy found no statistically significant improvement in activities of daily living as
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3 compared to a control group. However it was suggested that aspects of the care
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5 could provide some psychological support, although the perceived benefits of these
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7 to the recipients were not explored. It was concluded that rehabilitation programmes
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9 for such clients needed to be instigated and investigated to provide more evidence as
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11 to the most favourable interventions [15]. Identifying an ideal model of service
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13 provision for adults with NMD therefore seems to be the main challenge faced by
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15 health care providers.
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20 In this paper we will present the NeuroMuscular Centre (NMC), a voluntary sector
21
22 rehabilitation unit for adults with NMD, as an example of how services could be
23
24 provided for people with NMD. The NMC, a registered charity, offers a holistic
25
26 approach to care for clients from the North West of England and Wales by providing
27
28 a combination of services to its 360 registered users. Provision at the NMC includes
29
30 specialised physiotherapy, hydrotherapy, emotional support and information and
31
32 practical advice concerning NMD. Training on nationally accredited courses in
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34 Graphic Design and Information Technology (IT) is also offered. In addition, there is
35
36 the opportunity to gain employment in their graphic design and print company, or as
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38 administrators or fundraisers [18].
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45 A person-centred approach has been identified as a key factor in the provision of
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47 rehabilitation [12, 19]. One aspect of the person-centred approach to care is that it
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49 “strives to incorporate clients’ perspectives into the provision of services” [19, p.89]. It
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51 would therefore seem important to consider the NMC from the viewpoint of the
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53 people who use their services, in order to gain an understanding of their needs and
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55 how they can be supported to meet them. In addition there is a dearth of literature on
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57 adults with NMD and their experiences of rehabilitation. The aim of this study was
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3 therefore to gain an insight in to adults with NMD' perceptions of the NMC and what
4 they attained from attending for treatment, education or employment. The intention
5 was to develop an understanding of their experiences of the holistic service delivery
6 model offered by the NMC, and of their life with NMD.
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12 13 **Method** 14

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17 The research was qualitative in design and exploratory in nature, undertaken to
18 explore the particular phenomenon of adults with NMD who attended the NMC [20].
19 Posters inviting participation in the research were placed around the NMC. This led
20 to a self-selected purposive sample of nine participants being recruited from the
21 population of adults with NMD who attended the NMC for treatment, education or
22 employment. The sample which consisted of six males and three females, were aged
23 between 18 and 78 and had varying degrees of severity. Conditions included were
24 myotonic dystrophy, facioscapulohumeral MD (FSH) and Duchenne MD (one
25 participant from each condition) and Becker MD, spinal muscular atrophy (SMA) and
26 Charcot-Marie-Tooth disease (two participants from each condition). Of the
27 participants recruited eight were accessing physiotherapy treatment at the NMC; four
28 participants were also employees and two were attending courses in graphic design
29 and IT.
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49 Full informed consent was gained from all participants prior to commencement of the
50 study. Semi-structured interviews in the form of a discussion took place, allowing the
51 participant freedom to lead and develop the conversation.
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56 The following topic guide was used to facilitate discussion, follow- up questions
57 depended on individual responses to the topics given:
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3 Why do you come to the NMC?
4
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6 What is most important to you about attending the NMC?
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10 Take me through a typical day of attendance at the NMC
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13 Further questions were asked to gain demographic and background information:
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17 When and how were you referred to the NMC?
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19

20 What services do you access and how often?
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22

23 Tell me about your condition and how it affects you?
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25

26
27 It was hoped that exploration by the interviewer of the participant's insights could
28 then evolve, based on the response of the individual [21]. The interviews took place
29 at the NMC, thus ensuring an environment that was familiar to the participants.
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31

32
33 Interviews ranged in length from 45 minutes to one hour and 15 minutes, were
34 digitally recorded and transcribed verbatim. Transcribed interviews were then
35 imported into the NVivo7 software [22] for qualitative data analysis. Although coding
36 and analysis of the data remains the remit of the researcher, NVivo's usefulness is
37 that it provides a platform to store and manage data in an orderly fashion. Tools
38 available within the package allow reports and summaries of the analysis to be made
39 available (23).
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52 Ethical approval was granted by the Manchester Metropolitan University, Faculty of
53 Health, Psychology and Social Care Academic Ethics Committee. As the NMC is a
54 voluntary sector organisation and participants were not included in the study because
55 they were NHS users, NHS ethical approval was not required.
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Data analysis

Data analysis was inductive in nature as no hypothesis was being tested and the endeavour was to generate the findings purely from the data. The approach adopted involved thematic analysis leading to thematic networks [24]. The first stage of the procedure involves coding of the transcripts. In this present study transcriptions were read and re-read, including notes written about each dialogue, in order to familiarise the researcher with the data. The text was then subject to 'open coding' as described by Strauss and Corbin [25], where the data was coded based on salient issues identified from the text. This helped to divide the data into more manageable sections. The next stage, described by Attride-Stirling [24], is the identification of themes from the codes. In the present study, codes were first grouped together into themes based on recurring premises across the interviews. The Basic Themes are the lowest order ideas that provide a simple description of individual text but give little meaning to the text as a whole. It is only when these basic themes are arranged together under a common heading that summarises their main assumptions, that more insight into the text is given. These are known as the Organising Themes. A Global Theme is then derived by the collection together of related organising themes. It is the global theme that captures the essence of what the data is saying [24] (see table 1)

Table 1

Table 1 to be inserted here

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2
3 The themes were then organised into an interlinking network to assist with analysis
4 and interpretation of data. It is through defining the themes and their
5
6 interrelationships that a summary of the main findings is provided [24].
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11 Analysis is a dynamic process requiring the researcher to move back and forth from
12 the networks to the original data. It is through the exploration of each network and its
13
14 corresponding text that sense is made of the data and in-depth interpretation takes
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16 place [24].
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22 Memos and reflections of the researcher's thoughts were made throughout the
23 process to aid understanding and give meaning to the data. To improve credibility of
24 the research, two independent researchers were involved in the analysis and theme
25
26 discovery. This allowed the coding process to be cross checked to insure the
27
28 researcher had been true to the data. Themes identified were returned for participant
29
30 validation to verify that the insights captured were authentic in the eyes of the
31
32 interviewees.
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39 **Results**

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42 Two thematic networks evolved from the data with the global themes of: disparity in
43 service provision and physical and emotional well-being. Findings and discussion of
44
45 the thematic networks have been presented under the heading of the global and their
46
47 related organising themes. Direct quotes from participants have been included with
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49 pseudonyms given to participants to ensure anonymity.
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Thematic Network 1 Global theme: Disparity in service provision

Organising themes: Lack of specialist services/Limited knowledge of the condition

Only two of the participants had gained access to specialist services including physiotherapy on a regular basis. They had been diagnosed in their early childhood and were attending special schools, where they continued to receive this provision until leaving at the age of 16. All the other participants presented a different picture. They perceived that they were given limited knowledge about their situation and had a lack of awareness of the availability of specialist input to help them to manage their condition. Before attending the NMC these participants had had no access to physiotherapists who specialised in NMD, leading many to believe that they could only access physiotherapy for 'injury specific' but not 'condition specific' treatment.

Participants, who perceived that they had been given little or wrong information about their situation, appeared to be left with a naivety about their condition. Philip who has FSH said of his doctor:

'My GP assumed I had Becker because I was still alive. He thought he'd heard of Duchenne and Becker'

Ralph had 3 years of investigations before he was diagnosed with SMA. Although he had finally been given a 'label' for his condition he felt that the specialist had provided him with no comfort about the future when he remarked that:

... 'there was not the slightest hope and nothing can be done'.

1
2
3 It was 20 years later when he was referred to the NMC that Ralph was first given the
4 opportunity to gain specialist provision for his condition. Access to the services at the
5 NMC appeared to offer him '*encouragement*' and '*hope*' for the future that there was
6 something available to help him manage his situation. He highlighted this when
7 discussing his initial feelings at accessing the NMC:
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16 '*... I was quite surprised for the first time in my life there was something positive that*
17
18 *could be done...*'
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20 21 **Organising theme: Expert knowledge and skills** 22

23
24 It is therefore not surprising that one of the main benefits of attending the NMC,
25 perceived by participants, was access to specialists who had expert knowledge and
26 skills of their condition. What most participants saw as particularly advantageous was
27 that the staff recognised their circumstances and was able to tailor their input to their
28 individual needs. Peter said of the staff:
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37 '*... they do understand and as I say they know what level you can go to even as a*
38 *new person if a new person came up here they've got a good idea of what they're*
39 *going through before they've even actually met them and I think that's where the*
40 *specialist knowledge comes in.*'
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48 However what seemed most important to the participants was their physical status. In
49 particular they wanted to stay mobile and independent for longer. They therefore
50 identified the provision of ongoing physiotherapy whenever their condition required it,
51 as a significant benefit to accessing the NMC. It would seem that participants saw
52 regular treatment as necessary to help to delay their physical deterioration.
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3 As Rhianon commented:
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6 *'... thank God I can go to the Centre every week, because you'd just think what*
7
8 *would happen really, you'd go down hill pretty quick The thing is with MD you only*
9
10 *have to stop doing something for a short while, then you find you can't do it because*
11
12 *you're not using the muscles in the right way.'*
13
14

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16
17 That the participants perceived the staff at the NMC as experts who understood their
18
19 condition, appeared to give them more self-assurance that their condition could be
20
21 managed effectively. It was clear that they felt confident that the physiotherapists
22
23 knew exactly how much input they needed and what intervention was appropriate.
24
25 Receiving specialist rehabilitation in this way to improve or delay the decline in
26
27 physical capabilities seemed to help with psychological wellbeing. This was apparent
28
29 when a number of participants painted a depressing view of how they saw their future
30
31 if they hadn't accessed the NMC. As Ralph claimed:
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35
36 *'I would be an old man in a wheelchair, sitting at home; well happy enough in an old*
37
38 *man's way but you know bleak, bleak kind of life really'*
39
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42 **Thematic Network 2 Global theme: Physical and emotional wellbeing.**
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45 **Organising theme: Association with others**
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48 Socialising was identified by most of the participants as an important aspect of
49
50 attending the NMC. It seemed that the NMC provided a *'day out'* and an opportunity
51
52 to meet and *'banter'* with others and develop a *'wider social circle'*
53
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56 Nathan, who suffered from periods of depression since he was diagnosed with his
57
58 condition, found that attending the Centre enticed him out of the house because it
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3 gave him the chance to do something different and associate with other people. As
4
5 he said about coming to the NMC:
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9 *'It's the whole thing of coming out, it gives you a reason to have a wash and a shave*
10
11 *and put something on; put some nice clothes on, to come out.'*
12
13

14
15 However what seemed to be of particular benefit for some of the participants was the
16
17 opportunity to get together and converse with people who they felt they could identify
18
19 with. As David remarked about socialising at the NMC:
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21

22
23 *'it helps in a way ... you know that you've all got the same sort of troubles ... You*
24
25 *understand each other more, where someone who walks don't understand how hard*
26
27 *it is sometimes being in a wheelchair...'*
28
29

30
31 Sharing a common experience appeared to help to break down the barriers which
32
33 one is often faced with when first getting to know someone. Identifying with another
34
35 seemed to provide a familiarity, a depth to the understanding of the other person as
36
37 they recognised similarities in their circumstances. This appeared to create a sense
38
39 of connection and belonging. This was described by Ralph as he said:
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41

42
43 *'... outside there is a kind of a façade, ... when you meet a person you are not*
44
45 *meeting the person, you are meeting a façade that they have put up, a mask before*
46
47 *themselves. But here you start from moment one where the mask isn't there because*
48
49 *nobody here can put a mask on. ... it's so obvious and blatant that we are all in the*
50
51 *same neurological difficulty ... it's like here you join this club of like people'*
52
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55
56 It seems that interacting with people who had experienced similar circumstances
57
58 benefited the participants as it provided the opportunity for individuals to help and
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3 assist each other emotionally, particularly in times of need. Philip highlighted this
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5 when he said:

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8
9 *'... I know that I have the support here to advise along the way and there are lots of*
10
11 *people who've gone through it already who can help, you know that's a big thing*
12
13 *here, mutual support from people with MD and you know that everyone, whatever*
14
15 *you are going to go through, someone coming here has had that experience.'*
16
17

18
19 It was clear that through the ability to socialise and share recounts of their
20
21 experiences, the participants seemed to become more aware of restrictions with their
22
23 condition and possible ways of addressing them. Seeing other attendees with
24
25 limitations that they had not yet experienced appeared to be a particular benefit as
26
27 this was identified as an opportunity to plan for difficulties that they may encounter in
28
29 the future. As Peter claimed:

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33
34 *'you can see what other problems other people have and you can say well I've been*
35
36 *through that and I've got such and such a thing, now this helps me out.'*
37
38

39
40 One finding was the apparent difficulty in accepting the change in circumstance that
41
42 the condition bestowed on the participants. However it seemed that by sharing
43
44 information with others about themselves, participants felt supported to learn more
45
46 about their situation. Some participants identified that this helped them to be more
47
48 accepting of their condition. What became clear was that over a period of time being
49
50 part of this social network seemed to give the participants the potential to become
51
52 very knowledgeable about their circumstance. As Martin said:

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56
57 *'It helps me understand my condition and its often been said that people with*
58
59 *dystrophy they often become the experts but to become an expert you need to have*
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1
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3 *advice and input from other experts as well. So I think it helps me to come to terms*
4
5 *with it and then maybe I can share it ...'*
6
7

8 9 **Organising Theme: Sharing a commonality**

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11 It seemed that disablement conferred on the individual the feelings of difference and
12
13 uniqueness. When isolated from other people with the same condition this distinction
14
15 appeared to be seen in a negative light. As Ralph commented:
16
17

18
19
20 *'I was aware that unfortunately I'm a chap with a green face when green faces are*
21
22 *not common and green faces are unfortunately not a good thing to have.'*
23
24

25
26 It was only on accessing the NMC that it seemed apparent to Ralph that there were
27
28 other people with the same condition, as he said when attending the NMC:
29
30

31 *'I saw a lot of people with green faces.'*
32
33

34
35 Having no knowledge of individuals in similar circumstances seemed to be the
36
37 situation for a number of participants which appeared to lead to feelings of
38
39 estrangement and isolation. However it is clear that some of the participants didn't
40
41 want to feel a disparity with others and this often led to concealment of their
42
43 impairment and at times denial of their condition. As Zoe claimed:
44
45

46
47 *'... when I'm not here I have to try and be like everybody else ... outside I'm*
48
49 *constantly trying my hardest not to limp because I just know that people are gonna*
50
51 *look at me really strangely and say ooh, look at her walking down the street.'*
52
53

54
55 However at the NMC it was apparent that Zoe did not feel this need to hide her
56
57 impairment as she said of attending the NMC:
58
59

60 *'when I'm here I can walk around and I'm limping and no one looks at you twice.'*

1
2
3 Attending the NMC and experiencing a commonality with other people, therefore
4
5 appeared to challenge this perception of self. At the NMC since participants were
6
7 viewed to be no different from others and were accepted for who they were, it
8
9 appeared to give them the confidence to show the true reflection of self.
10
11

12
13 As Shonia said of the NMC:
14

15
16 *'they treat you as a normal person... I'm not regarded as a person with a disability.*
17
18 *..... I'm not judged in anyway here either. It's like I said a comfortable environment.'*
19
20

21 22 **Organising theme: Being part of something** 23

24
25 Participants identified opportunities for employment at the NMC and attendance on
26
27 training courses as one of its benefits. The NMC provides employment and education,
28
29 for attendees who may otherwise not have similar chances. These opportunities
30
31 seemed to provide participants with a goal to pursue, giving them purpose to their
32
33 lives. Philip who had taken up employment at the NMC highlighted this when he
34
35 claimed:
36
37

38
39 *'I have a lot of responsibility here and knowledge of the Centre so I think it really*
40
41 *helps me buy into the whole Centre and what we are actually doing and why we're*
42
43 *doing it. I think that certainly gives me a sense of self-purpose and it's rewarding.'*
44
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49
50 Zoe who was trained in graphic design had failed to gain employment in this field
51
52 because health restrictions meant she could only work part-time. Employment at the
53
54 NMC with the flexible working hours gave her the opportunity to have the career that
55
56 she had sought. Having this chance to take on meaningful work seemed to provide
57
58 motivation and encouragement to Zoe. This was apparent when she stated:
59
60

1
2
3 *'... just coming here has just made my dream come true really, it really has and I can*
4 *now achieve what I want to achieve, work part time and get everything out of it that I*
5 *wanted to.'*
6
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10
11 Attending courses in NMC's training suite gave participants the opportunity to
12 develop skills and gain qualifications to improve their chances for future employment.

13
14 Giving participants a new prospect appeared to confer on them a different
15
16 perspective of how they saw themselves. Not just a person with a condition or
17
18 impairment but someone with another function in life with something more to offer.
19
20
21

22
23 When discussing his attendance at the training suite David said:
24
25

26 *'it's made me feel like part of something, so it's changed me as a person in that way*
27 *and I know that I'm good at what I'm doing .. and it's made me more confident about*
28 *being in a wheelchair cos sometimes I used to get sick of it, but now I know there's*
29 *ways for me to do well and get a good job and stuff like that so it's changed my*
30 *outlook on life..'*
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32
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39 Providing attendees the platform to attain a new status also seemed to help to
40 develop self confidence and raise expectations of what could be achieved Rhianon
41 who previously had no self-belief that she could be capable of gaining paid
42 employment, became more self-assured after working at the NMC. She found that
43 the encouragement that she gained at the NMC and the skills that she had
44 developed there provided her with a springboard to attaining employment outside the
45
46 NMC. She has now been working for the same private employer for the last 8 years.
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Discussion

Participants' prior experiences support previous findings which highlight a deficiency of specialist services for adults with NMD [6,10,11]. Although children with long term conditions may be adequately provided for, often no comparable service is available for adults [26, 27]. This is particularly disturbing as six of the nine participants in this study were diagnosed during their teenage years or adulthood. The time of diagnosis, when the individual has to come to terms with their condition as they progress from health to ill health, is often distressing [28]. The teenage years are a particularly disturbing period as illness coincides with the normal physical and emotional changes which occur during adolescence [29]. Hence at a time when support is most needed, provision appears lacking. It would therefore seem that proposals in the UK for quality improvements, including timely access to specialist services for people with long term conditions [12, 30], are particularly relevant at this time. It is vital that these recommendations are therefore continued to be implemented. Providing inadequate or no access to specialist resources could lead to people with muscular dystrophy missing out on essential care that could be beneficial to their long term management [10]. Placing barriers in this way can lead to greater disablement [31].

Hope is the motivation that provides one with the determination to continue to strive and the courage to deal with adverse situations [32, 33]. Renz et al [34, p.148], assert 'there is a right to hope' as hope is the life force that keeps one going.

Therefore it seems that to diminish the possibility of hope by offering no solace that anything can be done, could not only weaken one's resolve to manage one's own circumstance, but deny one the right to a life worth living. This seems particularly

1
2
3 pertinent as hopelessness and helplessness at diagnoses was found to be common
4
5 psychological problems in adults with MD [4]. The NMC by providing appropriate and
6
7 supportive specialist care to help manage the condition could offer hope by creating
8
9 some realistic optimism about the future, thus fostering the resolve to cope with the
10
11 situation [31, 32].
12
13

14
15 As a progressive disease, MD leads to a continual loss of ability [28]. Uppal [35]
16
17 found that the more one was physically restricted the greater the reduction in
18
19 happiness levels. Although these findings have been challenged [36], it may be
20
21 possible that if the decline in body function is slow, emotional changes could be
22
23 overcome, as the individual has time to adapt to the new situation [37]. Therefore
24
25 physical rehabilitation, by helping to delay disease progression, could potentially
26
27 enhance emotional wellbeing. What has been claimed by adults with physical
28
29 disabilities is that engaging in physical activities provides them with psychological as
30
31 well as physical health benefits [38]. As NMD presents in a number of different ways
32
33 leading to a diversity of needs for the individual [4], it would therefore seem logical to
34
35 suggest that the specialist skills and expertise offered at the NMC are essential to
36
37 provide the management for this complex condition [8,10]. However due to the lack
38
39 of consensus as to an appropriate exercise regime for people with NMD [13], further
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41 research is required to identify the optimum physical intervention for this client group.
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50 We are defined by our relationships both with ourselves and with others. We
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52 construct an identity based on how we view ourselves, which is influenced by how
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54 people respond to us [39, 40]. Our character could therefore be said to be mutable,
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56 shaped by our experiences [41]. If people are stared at because of their physical
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58 restrictions it could confirm to them that they are different, deficient in some way, as if
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3 they don't live up to society's expectations of how they should be. This could present
4 a negative self perception, leading to vulnerability and low self-esteem [40].
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8 Concealment of their physical limitations could then be a way of trying to 'fit in' in an
9 attempt to facilitate a more positive reaction from others, or a way of denial of one's
10 condition in an attempt to feel more accepted. Although denial can improve coping in
11 the short-term by creating hope, long term it can preclude the individual from
12 observing their true self [32,40], hence limiting the potential for self-realisation.
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16 At the NMC attendees can observe others with similar limitations. Therefore as
17 physical restrictions are the commonality amongst people with NMD, participants
18 were not viewed as being different in any way. As a result of this acceptance of their
19 condition it appeared that the participants no longer felt the need to change their
20 behaviour. As attendees see similarities with others it could offset the feelings of
21 estrangement [40], which could help them view themselves in a more positive light,
22 thus limiting the need for self-pretence or denial. Delmar [32] claim that it is only
23 through self-acknowledgement and understanding that one can identify one's
24 condition and learn to live with it. The NMC, by creating an environment where one
25 feels comfortable to present one's true essence could therefore provide the only
26 opportunity where the individual experiences full acceptance for who they are. It is
27 this confirmation and regard from another that can facilitate self- humanity and
28 recognition [42, 43].
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52 Evidence suggests that social interaction improves wellbeing [44-46]. As it has been
53 found that restrictions caused by MD could limit the possibilities for social
54 engagement [28], coming to the NMC may offer the only opportunity to venture out
55 and meet others. Although what seems important to positive health is that the
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3 relationships formed are encouraging and worthwhile [47, 48]. The ability to identify
4 commonalities with others at the NMC appeared to cultivate these meaningful
5 associations by fostering mutual compassion and understanding. Sharing accounts
6 of their fears and aspirations for the future could provide the psychological support to
7 help individuals to deal with their circumstance, therefore improving wellbeing [33]. It
8 would seem reasonable to suggest that support from people who are more able to
9 comprehend one's situation and hence potentially more empathetic [49], could
10 provide an even greater benefit.
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23 Each Individual attending the NMC brings with them a wealth of knowledge gained
24 from their varied experiences [48]. Through engagement with one another,
25 information is shared about their condition and situations that they have encountered.
26 It is through these interactions that attendees can collectively facilitate self-
27 understanding which over time can develop expertise about their condition. The
28 training of individuals to become Expert Patients has been a Department of Health
29 initiative to support people with long term conditions [12, 50]. The NMC, as a learning
30 community, provides the environment for individuals to become their own expert
31 patients, thus fulfilling these expectations.
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45 It has been estimated that there are between 50% and 70% of people with disabilities
46 of working age unemployed in developed countries, and 80% to 90% of people with
47 disabilities of working age unemployed in developing countries [51]. It therefore
48 seems significant that the participants identified opportunities for employment at the
49 NMC and attendance on training courses as one of its benefits. The offer of work and
50 education provides the potential to improve the engagement of people with long term
51 conditions in employment [12, 52]. Increasing the level of education of individuals has
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3 been found to reduce the level of unemployment [53]. Therefore providing courses to
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5 improve skills could help to increase individuals' employability as they become more
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7 attractive prospects to employers. Improving employment opportunities could also
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9 provide economic benefits for the individual, through the procurement of a wage and
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11 for society, by reducing benefits [54, 55].
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16 Frankl [56, p133.] claimed that "creating a work or doing a deed" could provide life's
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18 purpose, a reason for living, leading to emotional benefits. However what seems
19
20 important to wellbeing is not the provision of work in itself, but that the endeavour
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22 undertaken is meaningful [44, 57]. The NMC by providing courses to improve
23
24 individuals' skills and attain qualifications could potentially enhance their ability to
25
26 gain more meaningful work. It could also be said that employment at the NMC in their
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28 graphic design and print company, or as administrators or fundraisers, provides
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30 opportunities for individuals to participate in a more significant way, thus promoting
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32 positive health.
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38 **Limitations**

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41 Some limitations are acknowledged in this study. Due to the uniqueness of personal
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43 experiences and the involvement of only one centre, transferability of the findings to
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45 other contexts or settings can not be assumed. However it is likely that situations
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47 highlighted by the participants would resonate with individuals in similar
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49 circumstances [20].
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54 A self-selected sample can be said to recruit more subjects who have something in
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56 particular to say about the Centre. It is therefore possible that the more passive
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58 individuals may not be represented. In this study four of the nine volunteers also
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3 worked for the print and design company or as fundraisers. It could therefore be said
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5 that their experiences could be perceived to be different to clients who are service
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7 users only. However these participants accessed a full range of provisions at the
8
9 NMC and therefore had a number of valuable experiences to share about their
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11 attendance at the NMC.
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16 The sample included a varied cross-section of subjects and by the ninth participant,
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18 repetition of information suggested saturation of themes, in that further analysis
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20 would be unlikely to identify any new codes [58].
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23 24 **Conclusion**

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26 It is apparent from these findings that there is still a lack of availability of specialist
27
28 treatment leading to a disparity of access for people with NMD. Policies to improve
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30 health and social care for people with long term conditions may promote attempts to
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32 address this in the UK. It is therefore hoped that this undertaking remains a
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34 commitment for the New Government. However it is clear that the issue of service
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36 provision for all adults with NMD will remain problematic until evidence as to what
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38 constitutes optimal care for this client group is sought and guidelines developed.
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44 The NMC offers one example of how services could be provided for adults with NMD.
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46 Findings from this study suggest that the holistic approach at the NMC provide
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48 physical, psychosocial and economic benefits for adults with NMD. Although a
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50 number of positive experiences were highlighted by participants, what seemed
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52 particularly important was the ability to access a number of specialised services at
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54 one site and engage with people who had personal experience of NMD.
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3 The multidisciplinary approach at the NMC, through the combination of healthcare,
4 support, education and employment, offers a unique model for rehabilitation. As an
5 enterprise, satellite centres adopting the ethos of the NMC could be created
6 supported by charitable funding and procuring contracts with NHS primary care
7 trusts. This would offer the potential to help to redress some of the inequalities and
8 inadequacies in health care for adults with NMD and improve their general well-
9 being.
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20 Although this study has shown some promising results, more research with a wider
21 range of participants needs to be undertaken to explore further the role of the NMC
22 and the holistic model of service provision. Specific areas for future research
23 identified by this study are:
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- 31 1. Investigations in to the most appropriate physical intervention for this client group
32 including type and intensity of exercise regime.
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- 34 2. Further exploration of the psychosocial needs of adults with NMD and how the
35 NMC could meet these needs, including how to cultivate an environment that
36 promotes mutually support and encourages the sharing of knowledge about the
37 condition.
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- 46 3. Ascertaining the feasibility of developing initiatives to facilitate return to work and
47 the gaining of meaningful employment for people with NMD including setting up
48 an advisory service at the NMC, job centre collaboration, college links and work
49 placements
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57 Although this research has been carried out in the UK there are implications for all
58 health care professionals involved in the provision of services for adults with NMD.
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3 Professionals need to be aware of the importance of providing a holistic approach to
4 care for adults with NMD to improve not only the physical health but also the
5 psychosocial wellbeing of this client group. A greater understanding of the
6 experiences and requirements of adults with NMD and what optimum care
7 represents to them is needed. It is only through these insights that an ideal model for
8 service provision can truly be developed.
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18
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20 their time and provided support to carry out this research.
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27 **Declaration of interest**

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29 The authors report no conflicts of interest. The authors alone are responsible for the
30 content and writing of the paper.
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References

- [1] Brown SC, Jimenez-Mallebera C. Biochemical and molecular basis of muscle disease. In Karpati G, Hilton-Jones D, Bushby K, Griggs RC, editors. Disorders of voluntary muscle. 8th ed. Cambridge: Cambridge University Press; 2010. p 37–80
- [2] Mukherjee M, Mittal B. Muscular Dystrophies. Indian Journal of Paediatrics 2004;71:161-8.
- [3] McDonald CM. Physical Activity, Health Impairments, and Disability in Neuromuscular Disease. American Journal of Physical Medicine & Rehabilitation 2002;81:108-120.
- [4] Ahlström G, Sjöden P-O. Coping with illness-related problems and quality of life in adult individuals with muscular dystrophy. Journal of Psychosomatic Research 1996;41:365-376.
- [5] Emery AE. Muscular Dystrophy. Third ed. Oxford: Oxford University Press 2008. p 1-3
- [6] Hill ME, Phillips MF. Service provision for adults with long-term disability: A review of services for adults with chronic neuromuscular conditions in the United Kingdom. Neuromuscular Disorders. 2006;16:107-112.
- [7] Norwood FL, Harling C, Chinnery PF, Eagle M, Bushby K, Straub V. Prevalence of genetic muscle disease in Northern England: in-depth analysis of a muscle clinic population. Brain 2009;132: 3175-3186
- [8] All Party Parliamentary group for Muscular Dystrophy. Access to Specialist Neuromuscular Care: The Walton Report. London: Muscular Dystrophy Campaign; 2009. p 7-11
- [9] Gibson BE, Young NL, Upshur RE, McKeever P. Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy. Social Science & Medicine 2007;65:505-517.
- [10] Muscular Dystrophy Campaign. Building on the Foundations: The need for a Specialist Neuromuscular Service across England. London: Muscular Dystrophy Campaign; 2007. p 2
- [11] Parker AE, Robb SA, Chambers AC, Davidson AC, Evans K, O'Dowd J, Williams AJ, Howard RS. Analysis of an adult Duchenne muscular dystrophy population. Quality Journal of Medicine 2005;98:729-736.
- [12] Department of Health. The National Service Framework for Long-term Conditions. London: The Stationary Office 2005.

- 1
2
3 [13] Kilmer DD. Response to Resistive Strengthening Exercise Training in
4 Humans with Neuromuscular Disease. *American Journal of Physical*
5 *Medicine & Rehabilitation* 2002;81:121-126.
6
7
8 [14] Wang CH, Finkel RS, Bertini ES, Schroth M, Simonds A, Wong B, Aloysius A,
9 Morrison L, Main M, Crawford TO, Trela A, and Participants of the International
10 Conference on SMA Standard of Care. Consensus Statement for Standard of
11 Care in Spinal Muscular Atrophy. *Journal of Child Neurology* 2007;22:1027-
12 1049.
13
14
15 [15] Ahlström G, Lindvall B, Wenneberg S, Gunnarsson LG. A comprehensive
16 rehabilitation programme tailored to the needs of adults with muscular
17 dystrophy. *Clinical Rehabilitation*. 2006;20:132-141.
18
19
20 [16] Pieterse AJ, Cup, EH, Knuijt S, Hendricks HT, Van Engelen BG, Van der Wilt
21 G-J, Oostendorp RA. Development of a tool to guide referral of patients with
22 neuromuscular disorders to allied health services. Part one. *Disability and*
23 *Rehabilitation*. 2008;30:855-862.
24
25
26 [17] Cup EH, Pieterse AJ, Knuijt S, Hendricks HT, Van Engelen BG,
27 Oostendorp RA, Van der Wilt G. Referral of patients with neuromuscular
28 disease to occupational therapy, physical therapy and speech therapy:
29 Usual practice versus multidisciplinary advice. *Disability and Rehabilitation*
30 2007;29:717-726.
31
32
33 [18] NeuroMuscular Centre. Social accounts and annual report and financial
34 statements. NMC 2007-08
35
36 [19] Cott CJ. Client-centred rehabilitation: what is it and how do we measure it?
37 *Physiotherapy* 2008:89-90
38
39
40 [20] Stake RE. *The Art of Case Study Research*. London: Sage Publications;
41 1995. p 8
42
43 [21] Seidman I. *Interviewing as Qualitative Research: A guide for researchers in*
44 *education and the social sciences*. 2nd Ed. New York: Teachers College
45 Press;1998. p 66
46
47
48 [22] QSR. NVivo. Version 7. Melbourne: QSR International Pty Ltd 2006. p. 18-30
49
50
51 [23] Pope C, Ziebland, S, Mays, N. Analysing qualitative data. *British Medical*
52 *Journal* 2000;320: p 114-6.
53
54 [24] Attride-Stirling J. Thematic networks: an analytic tool for qualitative research.
55 *Qualitative Research* 2001;1:385-405.
56
57
58 [25] Strauss A, Corbin J. *Basics of Qualitative Research: Techniques &*
59 *procedures for developing grounded theory*. 2nd Ed. London: Sage
60 Publications;1998. p 101-121.

- 1
2
3
4 [26] Department of Health. Transition: getting it right for young people: Improving
5 the transition of young people with long term conditions from children's to
6 adult health services. London: The Stationary Office 2006.
7
8
9 [27] Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to
10 adult health care for adolescents and young adults with chronic conditions.
11 Journal of Adolescent Health. 2003;33:309-311.
12
13 [28] Nätterlund B, Sjöden P-O, Ahlström G. The illness experience of adult persons
14 with muscular dystrophy. Disability and Rehabilitation. 2001;23:788-798.
15
16 [29] Michaud P-A, Suris J-C, Viner R. The adolescent with a chronic condition. Part
17 II: healthcare provision. Archives of Disease in Childhood. 2004;89:943-949.
18
19 [30] Darzi A. High quality care for all: NHS next stage review final report.
20 London: The Stationary Office 2008.
21
22 [31] Masala C, Petretto DR. From disablement to enablement: Conceptual models
23 of disability in the 20th century. Disability and Rehabilitation 2008;30:1233-
24 1244.
25
26 [32] Delmar C, Bøje T, Dylmer D, Forup, L, Jakobsen C, Møller, M, Sønder H,
27 Pedersen BD. Achieving harmony with oneself: life with a chronic illness.
28 Scandinavia Journal of Caring Sciences 2005;19:204-212.
29
30 [33] Sigurgeirsdottir J, Halldorsdottir S. Existential struggle and self-reported
31 needs of patients in rehabilitation. Journal of Advanced Nursing.
32 2007;61:384-392.
33
34 [34] Renz M, Koeberle D, Cerny T, Strasser F. Between utter despair and
35 essential hope. Journal of Clinical Oncology 2009;27:146-149.
36
37 [35] Uppal S. Impact of the timing, type and severity of disability on the subjective
38 well-being of individuals with disabilities. Social Science & Medicine
39 2006;63:525-539.
40
41 [36] Grootenhuis MA, de Boone J, van der Kooi AJ. Living with muscular
42 dystrophy: health related quality of life consequences for children and
43 adults. Health and Quality of Life Outcomes 2007;5:31
44
45 [37] Boström K, Nätterlund BS, Ahlström G. Sickness impact in people with
46 muscular dystrophy: a longitudinal study over 10 years. Clinical
47 Rehabilitation 2005;19:686-694.
48
49 [38] Ellis R, Kosma M, Cardinal BJ, Bauer JJ, McCubbin, JA. Physical activity
50 beliefs and behaviour of adults with physical disabilities. Disability and
51 Rehabilitation 2007;29:1221-1227.
52
53
54
55
56
57
58
59
60

- 1
2
3 [39] Goffman E. The presentation of self in everyday life. London: Penguin
4 Books 1990. p 30
5
6
7 [40] Strandmark M. Ill health is powerlessness: a phenomenological study
8 about worthlessness, limitations and suffering. Scandinavian Journal of
9 Caring Sciences 2004;18:135-144.
10
11 [41] Rhodes P, Nocon A, Small N, Wright J. Disability and identity: the challenge
12 of epilepsy. Disability & Society 2008;23:385-395.
13
14
15 [42] Watermeyer B, Swartz L. Conceptualising the psycho-emotional aspects of
16 disability and impairment: the distortion of personal and psychic boundaries.
17 Disability and Society 2008;23:599-610.
18
19
20 [43] Yar M. 'Recognition and the Politics of Human(e) Desire'. Theory, Culture &
21 Society 2001;18:57-76.
22
23 [44] McAllister F. Wellbeing: Concepts and Challenges. Discussion Paper
24 prepared for the Sustainable Development Research Network 2005.
25 [http://www.sdrnadmin.rechord.com/wp-content/uploads/sdrnwellbeingpaper-](http://www.sdrnadmin.rechord.com/wp-content/uploads/sdrnwellbeingpaper-final_000.pdf)
26 [final_000.pdf](http://www.sdrnadmin.rechord.com/wp-content/uploads/sdrnwellbeingpaper-final_000.pdf) . Accessed 2009 Feb 15.
27
28
29 [45] Steptoe A, O'Donnell K, Marmot M, Wardle J. Positive affect and psychosocial
30 processes related to health. British Journal of Psychology 2008;99:211-227.
31
32
33 [46] Donovan N, Halpern D. Life Satisfaction: the state of knowledge and
34 implications for government. London: Strategy Unit, Cabinet Office 2002.
35
36
37 [47] Seeman TE. Social ties and health: The benefits of social integration.
38 Annals of Epidemiology 1996;6:442-451.
39
40 [48] Eheart BK, Hopping D, Power MB, Mitchell ET, Racine D. Generations of
41 Hope Communities: An intergenerational neighborhood model of support and
42 service. Children and Youth Services Review. 2009;31:47-52.
43
44
45 [49] Hemmerdinger JM, Stoddart S, Lilford RJ. A systematic review of tests of
46 empathy in medicine. BMC Medical Education 2007;7:24
47
48
49 [50] Department of Health. Our health, our care, our say: a new direction for
50 community services. London: The Stationary Office 2006.
51
52 [51] Disability and Employment [Internet]. United Nations enable. Rights and
53 dignity of persons with disability. no date- [cited 2010 May 10]. Available from:
54 <http://www.un.org/disabilities/default.asp?id=255>
55
56 [52] Department for Work and Pensions. A new deal for welfare: Empowering
57 people to work. London: The Stationary Office 2006.
58
59
60

- 1
2
3 [53] Fowler WM, Abresch RT, KochTR, Brewer ML, Bowden RK, Wanlass RL.
4 Employment profiles in neuromuscular diseases. American Journal of
5 Physical Medicine and Rehabilitation 1997;76:26-37.
6
7
8 [54] The Prime Ministers Strategy Unit. Improving the life chances of disabled
9 people. London: Cabinet Office 2005.
10
11 [55] Department for Work and Pensions. Improving health and work: Changing
12 lives' the government's response to 'Working for a healthier tomorrow'.
13 London: The Stationary Office 2008.
14
15
16 [56] Frankl V. Man's search for meaning. New York: Washington Square
17 Press; 1985 p.133.
18
19
20 [57] New Economics Foundation (NEF). A well-being manifesto for a flourishing
21 society. London: NEF 2004.
22
23 [58] Flick U. An Introduction to Qualitative Research. California: Sage
24 Publications 1998 p 185
25
26
27
28
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Identified themes from the experiences of adults with NMD attending a neuromuscular centre

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BASIC THEMES

ORGANISING THEME

GLOBAL THEMES

Limited awareness of services available →
 Few specialists in the condition →

Lack of specialist services →

Disparity in service provision

Misinformed →
 No hope →

Limited knowledge of the condition →

Physical and emotional wellbeing

Independent for longer →
 Client centred →
 Self-empowerment →

Expert knowledge and skills →

Supportive environment →
 Understanding of situation →
 Equality challenges difference →

Sharing a commonality →

Socialisation →
 Sense of belonging →
 Learning through shared experiences →

Association with others →

Purpose →
 Giving back by helping others →

Being part of something →