

1 **Collaborative goal setting with adults attending physiotherapy at a specialist**
2 **neuromuscular centre - is it always appropriate? A cross sectional survey**

3

4 **Abstract**

5 Objectives: Collaborative goal setting is an integral component of treatment planning
6 for adults with neuromuscular disorders (NMD). However due to the unique
7 challenges for these individuals, identifying a process for goal setting that is
8 advantageous for all, can be problematic. This study aimed to evaluate collaborative
9 goal setting at a specialist Neuromuscular Centre, as reported by service users
10 attending physiotherapy. It also, aimed to generate discussion about collaborative
11 goal setting and the practice of goal setting in adults with NMD, in order to inform
12 future practice.

13 Design: A cross-sectional survey design was used.

14 Setting: A specialist NMD community based centre in the UK

15 Participants: Adults with NMD who attended the Centre.

16 Interventions: Themes and content analysis of goals set were carried out alongside
17 demographic data collection.

18 Results: 104 clients (34 females) with a range of neuromuscular conditions including;
19 Becker, facioscapularhumeral, limb girdle, Duchenne and myotonic muscular
20 dystrophies completed the survey. Thirty six respondents (37%) stated they had set
21 goals with the physiotherapist whilst 62 (63%) stated they did not. Respondents'
22 goals were grouped into four themes: maintenance, symptom management,
23 improving physical condition and learning to live with the condition.

24 Conclusions: Readiness to take part in collaborative goals setting is unique to each
25 individual. Physiotherapists need to be skilful in supporting adults with NMD through
26 the goal setting process until they are capable of sharing responsibility. Setting
27 personal goals to improve emotional wellbeing may help to develop confidence to
28 take more control of their situation, hence facilitating skills in self-management.

29 **Key words**

30 Neuromuscular disorders, goal setting, self-management, long-term conditions

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51 **Introduction**

52 Muscular dystrophy and its related neuromuscular disorders (NMD) are a frequently
53 hereditary and diverse group of conditions that lead to abnormal muscle pathology
54 with resultant muscle weakness and functional loss (1-5). Although, there is still no
55 consensus on optimal physiotherapy for these disorders and a lack of specific
56 guidelines for their management, collaborative goal setting is considered an integral
57 component of the rehabilitation process (6-9). Collaborating, by working in
58 partnership with patients to reach a consensus when goal setting, is also a
59 requirement to meet professional standards for physiotherapy (10-11).

60 There are many benefits to collaborative goal setting including encouraging patient
61 active participation in their management, providing shared outcomes for clinicians
62 and patients to work towards, and facilitating patients to become more self-
63 determining (12-17). However, there are inconsistencies in its use amongst
64 clinicians, with a lack of a defined approach for collaboration (6, 18-21). Patients also
65 need to want, and have the ability, to participate in the process (8, 22-23).

66 Following a structured format when setting goals has been found to be more likely to
67 engage patients and be more patient centred (14, 24). However, there is
68 inconclusive evidence that structuring goal setting is more effective in achieving
69 outcomes (9, 24-25). This suggests that the process alone cannot be credited for
70 successful goal attainment. Indeed, the promotion of focussed goals that are
71 meaningful to the patient recognises the importance of the type of goals set (10, 17).
72 If patients perceive goals are relevant to them, with a worthwhile outcome, then they

73 are more likely to want to undertake and achieve them (13, 25). Consequently, to
74 ensure goals are significant to the patient, a partnership where patients are
75 supported to take an active role in shaping these goals is likely to be essential (17,
76 21). However, collaborating in this way has been found to be problematic with
77 clinicians' and patients' expectations of roles and what can be achieved conflicting,
78 with differing views on which goals are important or achievable (6, 12, 20-21, 23).
79 This is even more complex for individuals with NMD as access to regular, specialist
80 physiotherapy is often limited (26-27). This means that the opportunity for adults with
81 NMD to be guided through the goal setting process, including identifying and
82 monitoring appropriate goals, is likely to be inconsistent at best.

83 The catalyst for this article arose when data from a previous study, on the utilization
84 of physiotherapy at a Neuromuscular Centre (NMC), highlighted that many clients
85 reported that they had not set goals with their physiotherapist (28). When the authors
86 collected the data, collaborative goal setting was usual physiotherapy practice at the
87 NMC, but there was no set procedure amongst the physiotherapists for undertaking
88 this process (29). This study aims to evaluate goal setting at the NMC, as viewed by
89 service users who attend for physiotherapy. The intention is to gain insight into what
90 may influence clients' reporting of goal setting, the type of goals set and how clients
91 articulate these. A secondary aim of this study is to generate discussion around
92 collaborative goal setting and to consider the practice of goal setting in adults with
93 NMD, in order to inform future practice.

94 **Methods**

95 *Participants*

96 One hundred and thirty three clients who attended for physiotherapy at the NMC
97 between July and September 2010 were invited to participate.

98 *Design*

99 A prospective, cross sectional survey of adult users of the NMC physiotherapy
100 service was employed for this study.

101 *Questionnaire*

102 Questions analysed for this study were part of a 13-item questionnaire that was
103 developed to evaluate physiotherapy provision at the NMC. Two questions that
104 asked if participants had set goals with their physiotherapist and whether they were
105 satisfied with the physiotherapy provision were used in order to gain some insight
106 into goal setting at the NMC and whether this influenced their satisfaction with the
107 physiotherapy they received. Participants were also requested to record the goals
108 that they had set with their physiotherapist. This information was collated with
109 demographic details of all participants.

110 Following an initial pilot of the questionnaire with 9 service users, the finalised
111 questionnaire with detailed information of the study, was given to all clients aged 18
112 or over, when they attended for physiotherapy between the period July to September
113 2010. To ensure anonymity was maintained, each participant was asked to include a
114 unique code on the questionnaire that was identifiable only to them, should they wish
115 to withdraw their information.

116 *Data analysis*

117 All data collected were summarised and presented descriptively.

118 The participants' goals were analysed thematically with open coding. An established
119 framework for identifying goal setting themes was not used as the researchers aimed
120 to construct an interpretation of the nature of the goals from the participants'
121 perspective rather than forcing them into preconceived categories (30). Using this
122 inductive process is a distinct approach to the quantitative methods used to initially

123 describe the data (31). By viewing the same social experience from different
124 perspectives, the authors aimed to draw on the strengths of both methods, in order
125 to give a broader account of the goal-setting phenomenon (31-32).
126 Goals were initially coded independently by the two authors (SH and RS). Both
127 repeatedly read the goals to gain an overview before writing a word or phrase by the
128 side of each that reflected the nature of the goal prior to meeting to develop the
129 themes. Goals that were deemed as similar were grouped together into subthemes.
130 Related subthemes were then further combined to form the overarching theme of the
131 goals that were set. Any initial differences in theme labelling was resolved through
132 reflective dialogue by the authors and the creation of diagrammatic representations
133 of themes with their associated goals (tabulated in Table 1). To improve credibility a
134 third researcher (DO) peer reviewed the process and corroborated the findings.
135 Goals related to their overarching themes were then subjected to content analysis
136 (33).

137 **Results**

138 A total of 133 clients accessed physiotherapy at the NMC during the survey period,
139 of which 125 chose to take the questionnaire and 8 declined. By the finalised dated
140 for return of questionnaires, 104 participants (78%), had completed and returned the
141 questionnaires by stamp address envelope or in person when attending the
142 physiotherapy department. They had a range of neuromuscular conditions including;
143 Becker, facioscapularhumeral, limb girdle, Duchenne and myotonic muscular
144 dystrophies, spinal muscular atrophy and Charcot - Marie -Tooth disease. There
145 were 70 males and 34 females with a median age of 45 years (IQR:35.3 to 58.8
146 years). They were a median average of 19.5 years after diagnosis (IQR: 12-30
147 years). Seventeen participants (16.3%) could complete all activities unaided, 54

148 participants (52%) required some assistance to complete daily activities, 23 (22.1%)
149 required assistance for all tasks and 10 (9.6%) could not complete most daily tasks
150 (see (28), for more detailed demographic information). From those that completed
151 the questions on goal setting (98), 36 (37%) reported they had set goals with the
152 physiotherapist and 62 (63%) stated they did not (see table 2). From those that
153 answered item on satisfaction (101), 99 (99%) reported that they were satisfied with
154 the physiotherapy provision and 1/101 (1%) said they were not.

155 *Themes*

156 There were 65 goals identified by the participants. The goals were combined into 4
157 overarching themes.

158 1. *Symptom management*

159 Twenty percent of goals (13/65) were concerned with ways to manage symptoms.
160 These were mainly physical management but also goals for helping with pain relief,
161 particularly back pain. Although participants were asked to list the goals they had set,
162 these were not always articulated as goals in the same way that physiotherapists
163 would be expected to communicate goals with their patients. This occurred in all
164 categories but especially under this theme. A number of goals were related to
165 completion of exercises that they were to carry out and equipment that they were to
166 use, rather than functional goals to work towards. For instance, one participant
167 included as a goal, 'active exercises with arm pedals' and another participant wrote
168 'tilt table, for standing' as their current goal. Other participants just recorded one or
169 two words under goals set. For example, one wrote 'stretches' and another wrote
170 'ball exercises'. Whilst these are likely to interlink with other themes, these were
171 labelled together under symptom management because they could all be related to
172 helping the symptoms in one way or another.

173 2. *Maintenance*

174 Thirty one percent of goals were related to maintenance (20/65). Goals that were
175 identified under this theme were related to preserving the status quo in order to
176 maintain their condition and prevent deterioration. Most goals were concerned with
177 maintaining mobility, including joint range of motion as well as sustaining the ability
178 to continue ambulation. Two maintenance related goals were concerned with
179 maintaining muscle strength.

180 3. *Improving physical status*

181 Twenty one percent (14/65) of goals were related to improving physical condition.
182 These were primarily concerned with muscle strengthening, including core stability
183 and goals for improving mobility, specifically joint flexibility, and standing time. Goals
184 to improve the ability to carry out an activity were also identified as well as goals for
185 losing weight.

186 4. *Learning to live with the condition*

187 The remaining 28% of goals (18/65) were related to learning to live with the
188 condition. These were mainly concerned with improving emotional state including
189 reducing depression, boosting morale and keeping a positive outlook on life. Goals
190 were also identified that referred to learning to cope with their problems including
191 pain management and confidence in carrying out activities. There were also a
192 number of goals related to carrying out home exercise regimes.

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194 **Discussion**

195 This study aimed to describe and evaluate goal setting in clients attending the NMC
196 for physiotherapy. The findings indicate that females and those over the age of 65
197 years appeared to be most likely to report that they had set goals, irrespective of the

198 time since diagnosis or how long they had been attending for physiotherapy.
199 However, only 37% of participants reported that they had set goals with their
200 physiotherapist whilst 63% of participants were not aware of their participation in a
201 goal setting process. This is consistent with previous research that has found a
202 disparity between clinicians' and patients' perception of goal setting and the
203 clinicians' belief that they had set goals with their patients which was not
204 corroborated by the patients (12, 34). Whilst physiotherapists are practised in a
205 formalised process of goal setting, many patients may have had limited or no
206 previous experience in setting goals (34), so their interpretation of goals and the
207 process of goal setting, is likely to be different (6, 20, 35). This was highlighted in this
208 study as when participants were asked to list the goals that they had set; some listed
209 equipment to use or how they were going to achieve the goal rather than an actual
210 goal they were working towards. Others had omitted to write down what their goals
211 were. It is not clear if this was because these participants were unable to articulate
212 their goals or recall the goals that had been set. However, a number of goals written
213 by other participants were explicit and comprehensible, suggesting that there could
214 also, be differences in understanding or communication of goals. Indeed, how
215 clinicians communicate goals has been found to be important to help patients
216 understand and share decisions when goals setting (12, 15). As each interaction with
217 their patients will be unique, physiotherapists need to ensure they are versatile in
218 their language, to ensure goal setting is an inclusive process (12, 34).
219 Many people with NMD face progressive physical changes, which for many lead to a
220 sense of self-loss until they become accepting of their new circumstances (26, 36).
221 As people with NMD go through these different stages, the capacity to deal with their
222 situation and take control of their life varies (4, 26). Consequently, there may be

223 occasions when wanting, or having the emotional ability to take an active role in goal
224 setting, may be diminished (8, 22-23). In this situation therefore, it would seem,
225 collaborative goal setting is not desirable, as patients only feel able to take a more
226 passive role within the process (15, 35). Indeed, goal setting may not have been an
227 important consideration for participants, as 99 per cent reported that they were
228 satisfied with the physiotherapy service they received whether they had reported
229 setting goals with their physiotherapist or not.

230 Lloyd (23:154) identified a 'continuum' for goal setting ranging from physiotherapist
231 led to patient led goals with collaborative goal setting lying somewhere in the middle.
232 It would seem individuals' aptitude for goal setting will fluctuate along this spectrum,
233 depending on where they are on their own life course and how they are coping with
234 challenges (23, 37). As can be seen in this study, the highest numbers of goal setters
235 were within the most independent (no assistance to carry out functional tasks) and
236 most dependent groups (unable to carry out most tasks). It may be that the most
237 independent individuals had not yet had to face life-changing situations. Conversely,
238 the more dependent participants may have learnt ways to manage and cope with
239 their situation, so were more capable of taking responsibility in goal setting (23, 26).
240 This suggests that physiotherapists need to be adaptable when setting goals, being
241 more attuned to where patients lie along the spectrum and their readiness to take
242 part in a collaborative process (15, 23). Physiotherapists at the NMC are specialists
243 in NMD and have, in many cases, developed close working relationships with their
244 clients. This could indicate that they intuitively have a greater understanding of the
245 goal setting abilities of their clients and so are responsive and adaptable to the
246 current capability of their patients to collaborate in the goal setting process. This

247 could be investigated in future work by identifying physiotherapists' views and
248 practices in collaborative goal setting in this patient group.

249 As NMD is progressive in nature (1-2), many of the goals set were related to
250 maintenance of an individuals' condition, particularly with preserving mobility and
251 staying ambulant. This is not surprising, as retaining independence has been found
252 to be a particular worry for people with NMD (26, 28).

253 However, the second highest number of goals was concerned with helping
254 individuals to cope and live with their condition by improving their emotional state:
255 including confidence building and carrying out home exercise programmes.

256 Individuals who are confident with good psychological health are more likely to want
257 and have the potential to take more accountability in planning their future (22, 38).

258 Consequently, goals to improve coping and wellbeing are likely to facilitate the
259 individual's ability to progress along the goal-setting spectrum and enable them to
260 take an active part in goal setting; thus providing them with an important tool for
261 developing self-management skills (15-16). Crucially, supporting individuals to
262 regulate themselves in this way is now seen as an integral part of patient
263 management for people with long-term conditions (17, 39-40). This may be
264 particularly pertinent for many individuals with NMD who have limited access to
265 specialist physiotherapy (26-27) and consequently need means to take care of
266 themselves in the community. Whilst goal setting is an important element in the
267 management of people with NMD, what seems essential is not only to consider the
268 type of goals set but the evolving process of goal setting as individuals with NMD
269 negotiate their path through life. Ways to translate this to the community setting,
270 particularly for people who have restricted access to specialist physiotherapy, to
271 guide individuals through a goal setting process, now needs to be explored.

272 *Limitations*

273 The authors acknowledge the limitations of this research as, although there was a
274 78% response rate (104 out of 133), only 36 participants claimed they had set goals
275 with the physiotherapist which is an interesting finding worthy of further research.
276 Nonetheless, the small number of respondents who set goals and the use of a single
277 specialist centre restricts the transferability of the findings to other settings, so future
278 research is needed to corroborate these results. Further exploration of goal setting
279 from the viewpoint of the physiotherapists at the NMC would also inform debate on
280 the goal setting process for this patient group.
281 However, the findings of this study describe aspects of goal setting and highlight
282 potential issues with setting goals for people with NMD. They also promote debate
283 around issues such as the role of collaborative goal setting for individuals with NMD,
284 the type of goals to be set and how can goal setting be optimised to improve the
285 lives of people living with NMD in the community.

286 **Conclusion**

287 In this study, the majority of respondents reported that they did not set goals; from
288 those that did, goals centred around themes of symptom management,
289 maintenance, improving physical status and learning to live with the condition.
290 Whilst it is recognised that physiotherapists undertake collaborative goal setting with
291 their patients, this is not always actualised (6, 23, 34). As there may be times when
292 individuals are not ready to share decision-making, it may be that collaborative goal
293 setting may not always be appropriate. In these instances, physiotherapists could
294 consider the optimum way to guide their patients along the goals setting spectrum,
295 until they develop their capability to take part in the process. Equally,
296 physiotherapists need to be versatile in their language so that patients with varied

297 experiences of goal setting can make sense and contribute to the process. It is likely
298 that setting personal goals that help individuals to improve their emotional wellbeing
299 will help to endow them with the confidence to take more control of their situation.
300 Effective goal setting could therefore be a valuable resource for physiotherapists, not
301 only to support people with NMD to take more responsibility in their own future
302 planning, but to facilitate self-management skills, so that individuals with NMD can
303 learn to live a more independent life in the community.

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305 *Ethic approval:* Ethical permission for the original study was gained from Manchester
306 Metropolitan University, Department of Exercise and Sports Science academic
307 Ethics Committee (IPS approval code 11.02.10(ii)).

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309 *Conflict of interest:* The authors report no declarations of interest.

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