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

Abstract

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

Design: A cross-sectional survey design was used.

Setting: A specialist NMD community based centre in the UK

Participants: Adults with NMD who attended the Centre.

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

Results: 104 clients (34 females) with a range of neuromuscular conditions including; Becker, facioscapularhumeral, limb girdle, Duchenne and myotonic muscular dystrophies completed the survey. Thirty six respondents (37%) stated they had set goals with the physiotherapist whilst 62 (63%) stated they did not. Respondents’ goals were grouped into four themes: maintenance, symptom management, improving physical condition and learning to live with the condition.
Conclusions: Readiness to take part in collaborative goals setting is unique to each individual. Physiotherapists need to be skilful in supporting adults with NMD through the goal setting process until they are capable of sharing responsibility. Setting personal goals to improve emotional wellbeing may help to develop confidence to take more control of their situation, hence facilitating skills in self-management.

Key words

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

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

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

Following a structured format when setting goals has been found to be more likely to engage patients and be more patient centred (14, 24). However, there is inconclusive evidence that structuring goal setting is more effective in achieving outcomes (9, 24-25). This suggests that the process alone cannot be credited for successful goal attainment. Indeed, the promotion of focussed goals that are meaningful to the patient recognises the importance of the type of goals set (10, 17).

If patients perceive goals are relevant to them, with a worthwhile outcome, then they
are more likely to want to undertake and achieve them (13, 25). Consequently, to ensure goals are significant to the patient, a partnership where patients are supported to take an active role in shaping these goals is likely to be essential (17, 21). However, collaborating in this way has been found to be problematic with clinicians’ and patients’ expectations of roles and what can be achieved conflicting, with differing views on which goals are important or achievable (6, 12, 20-21, 23). This is even more complex for individuals with NMD as access to regular, specialist physiotherapy is often limited (26-27). This means that the opportunity for adults with NMD to be guided through the goal setting process, including identifying and monitoring appropriate goals, is likely to be inconsistent at best. The catalyst for this article arose when data from a previous study, on the utilization of physiotherapy at a Neuromuscular Centre (NMC), highlighted that many clients reported that they had not set goals with their physiotherapist (28). When the authors collected the data, collaborative goal setting was usual physiotherapy practice at the NMC, but there was no set procedure amongst the physiotherapists for undertaking this process (29). This study aims to evaluate goal setting at the NMC, as viewed by service users who attend for physiotherapy. The intention is to gain insight into what may influence clients’ reporting of goal setting, the type of goals set and how clients articulate these. A secondary aim of this study is to generate discussion around collaborative goal setting and to consider the practice of goal setting in adults with NMD, in order to inform future practice.

**Methods**

**Participants**

One hundred and thirty three clients who attended for physiotherapy at the NMC between July and September 2010 were invited to participate.
A prospective, cross sectional survey of adult users of the NMC physiotherapy service was employed for this study.

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

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

All data collected were summarised and presented descriptively. The participants' goals were analysed thematically with open coding. An established framework for identifying goal setting themes was not used as the researchers aimed to construct an interpretation of the nature of the goals from the participants' perspective rather than forcing them into preconceived categories (30). Using this inductive process is a distinct approach to the quantitative methods used to initially
describe the data (31). By viewing the same social experience from different
perspectives, the authors aimed to draw on the strengths of both methods, in order
to give a broader account of the goal-setting phenomenon (31-32).
Goals were initially coded independently by the two authors (SH and RS). Both
repeatedly read the goals to gain an overview before writing a word or phrase by the
side of each that reflected the nature of the goal prior to meeting to develop the
themes. Goals that were deemed as similar were grouped together into subthemes.
Related subthemes were then further combined to form the overarching theme of the
goals that were set. Any initial differences in theme labelling was resolved through
reflective dialogue by the authors and the creation of diagrammatic representations
of themes with their associated goals (tabulated in Table 1). To improve credibility a
third researcher (DO) peer reviewed the process and corroborated the findings.
Goals related to their overarching themes were then subjected to content analysis
(33).

Results
A total of 133 clients accessed physiotherapy at the NMC during the survey period,
of which 125 chose to take the questionnaire and 8 declined. By the finalised dated
for return of questionnaires, 104 participants (78%), had completed and returned the
questionnaires by stamp address envelope or in person when attending the
physiotherapy department. They had a range of neuromuscular conditions including;
Becker, facioscapularhumeral, limb girdle, Duchenne and myotonic muscular
dystrophies, spinal muscular atrophy and Charcot - Marie -Tooth disease. There
were 70 males and 34 females with a median age of 45 years (IQR:35.3 to 58.8
years). They were a median average of 19.5 years after diagnosis (IQR: 12-30
years). Seventeen participants (16.3%) could complete all activities unaided, 54
participants (52%) required some assistance to complete daily activities, 23 (22.1%) required assistance for all tasks and 10 (9.6%) could not complete most daily tasks (see (28), for more detailed demographic information). From those that completed the questions on goal setting (98), 36 (37%) reported they had set goals with the physiotherapist and 62 (63%) stated they did not (see table 2). From those that answered item on satisfaction (101), 99 (99%) reported that they were satisfied with the physiotherapy provision and 1/101 (1%) said they were not.

Themes

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

1. **Symptom management**

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

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

3. Improving physical status

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

4. Learning to live with the condition

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

Discussion

This study aimed to describe and evaluate goal setting in clients attending the NMC for physiotherapy. The findings indicate that females and those over the age of 65 years appeared to be most likely to report that they had set goals, irrespective of the
time since diagnosis or how long they had been attending for physiotherapy.

However, only 37% of participants reported that they had set goals with their physiotherapist whilst 63% of participants were not aware of their participation in a goal setting process. This is consistent with previous research that has found a disparity between clinicians’ and patients’ perception of goal setting and the clinicians’ belief that they had set goals with their patients which was not corroborated by the patients (12, 34). Whilst physiotherapists are practised in a formalised process of goal setting, many patients may have had limited or no previous experience in setting goals (34), so their interpretation of goals and the process of goal setting, is likely to be different (6, 20, 35). This was highlighted in this study as when participants were asked to list the goals that they had set; some listed equipment to use or how they were going to achieve the goal rather than an actual goal they were working towards. Others had omitted to write down what their goals were. It is not clear if this was because these participants were unable to articulate their goals or recall the goals that had been set. However, a number of goals written by other participants were explicit and comprehensible, suggesting that there could also, be differences in understanding or communication of goals. Indeed, how clinicians communicate goals has been found to be important to help patients understand and share decisions when goals setting (12, 15). As each interaction with their patients will be unique, physiotherapists need to ensure they are versatile in their language, to ensure goal setting is an inclusive process (12, 34).

Many people with NMD face progressive physical changes, which for many lead to a sense of self-loss until they become accepting of their new circumstances (26, 36). As people with NMD go through these different stages, the capacity to deal with their situation and take control of their life varies (4, 26). Consequently, there may be
occasions when wanting, or having the emotional ability to take an active role in goal setting, may be diminished (8, 22-23). In this situation therefore, it would seem, collaborative goal setting is not desirable, as patients only feel able to take a more passive role within the process (15, 35). Indeed, goal setting may not have been an important consideration for participants, as 99 per cent reported that they were satisfied with the physiotherapy service they received whether they had reported setting goals with their physiotherapist or not.

Lloyd (23:154) identified a ‘continuum’ for goal setting ranging from physiotherapist led to patient led goals with collaborative goal setting lying somewhere in the middle. It would seem individuals’ aptitude for goal setting will fluctuate along this spectrum, depending on where they are on their own life course and how they are coping with challenges (23, 37). As can be seen in this study, the highest numbers of goal setters were within the most independent (no assistance to carry out functional tasks) and most dependent groups (unable to carry out most tasks). It may be that the most independent individuals had not yet had to face life-changing situations. Conversely, the more dependent participants may have learnt ways to manage and cope with their situation, so were more capable of taking responsibility in goal setting (23, 26).

This suggests that physiotherapists need to be adaptable when setting goals, being more attuned to where patients lie along the spectrum and their readiness to take part in a collaborative process (15, 23). Physiotherapists at the NMC are specialists in NMD and have, in many cases, developed close working relationships with their clients. This could indicate that they intuitively have a greater understanding of the goal setting abilities of their clients and so are responsive and adaptable to the current capability of their patients to collaborate in the goal setting process. This
could be investigated in future work by identifying physiotherapists’ views and
practices in collaborative goal setting in this patient group.

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

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

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

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

The authors acknowledge the limitations of this research as, although there was a 78% response rate (104 out of 133), only 36 participants claimed they had set goals with the physiotherapist which is an interesting finding worthy of further research. Nonetheless, the small number of respondents who set goals and the use of a single specialist centre restricts the transferability of the findings to other settings, so future research is needed to corroborate these results. Further exploration of goal setting from the viewpoint of the physiotherapists at the NMC would also inform debate on the goal setting process for this patient group.

However, the findings of this study describe aspects of goal setting and highlight potential issues with setting goals for people with NMD. They also promote debate around issues such as the role of collaborative goal setting for individuals with NMD, the type of goals to be set and how can goal setting be optimised to improve the lives of people living with NMD in the community.

Conclusion

In this study, the majority of respondents reported that they did not set goals; from those that did, goals centred around themes of symptom management, maintenance, improving physical status and learning to live with the condition. Whilst it is recognised that physiotherapists undertake collaborative goal setting with their patients, this is not always actualised (6, 23, 34). As there may be times when individuals are not ready to share decision-making, it may be that collaborative goal setting may not always be appropriate. In these instances, physiotherapists could consider the optimum way to guide their patients along the goals setting spectrum, until they develop their capability to take part in the process. Equally, physiotherapists need to be versatile in their language so that patients with varied
experiences of goal setting can make sense and contribute to the process. It is likely
that setting personal goals that help individuals to improve their emotional wellbeing
will help to endow them with the confidence to take more control of their situation.
Effective goal setting could therefore be a valuable resource for physiotherapists, not
only to support people with NMD to take more responsibility in their own future
planning, but to facilitate self-management skills, so that individuals with NMD can
learn to live a more independent life in the community.

*Ethic approval:* Ethical permission for the original study was gained from Manchester
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*Conflict of interest:* The authors report no declarations of interest.

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