

Goal-directed physical activities in group rehabilitation and impact on health-related quality of life and participation among young adults with physical disabilities – a qualitative study

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ABSTRACT

Goal-directed rehabilitation is a common approach for people with physical disabilities of neurological origin. The effect of rehabilitation is often investigated with quantitative methods. There is little knowledge on if and how this approach influences health-related quality of life (HRQOL) and participation in their everyday life. The purpose of this study was to gain insight into how goal-directed rehabilitation with adapted functional activities in a group setting influenced HRQOL and participation in everyday life for young adults with disabilities of neurological origin using qualitative methods. Young adults ($n=6$) who had undertaken a goal-directed rehabilitation program participated in qualitative interviews. Data were analyzed through systematic text condensation. We found that goal-directed rehabilitation in a group setting was demanding, but motivating and rewarding due to the social aspects of group training and goal-achievements. In conclusion, the group setting was a positive context due to the social aspect, despite a heterogeneous group composition. Enhanced functional skills promoted HRQOL through increased participation in sport and increased independence in activities of daily living. In further, interventions aiming to increase HRQOL among this population, therapists should emphasize adapted physical activity to avoid increased fatigue and prioritize exercises in groups or pairs.

ARTICLE HISTORY

Received 20 October 2016
Revised 28 February 2017
Accepted 4 March 2017
Published online 21 March 2017

KEYWORDS

Health-related quality of life; rehabilitation; young adults; physical disability; participation

Introduction

Young adults with physical disabilities of neurological origin, such as cerebral palsy (CP) or spina bifida often struggle when participating in physical activities due to motor problems and physical fatigue, which influence the maintenance of their functional skills and health-related quality of life (HRQOL) [1,2]. The term HRQOL has evolved since 1980s to incorporate every aspects of overall quality of life that can clearly show to affect health – either physical or mental [3,4]. For clarification in this particular study, the authors focus on the individual level of HRQOL and include physical and mental health perceptions (energy level, mood) and their correlates – including functional status, participation and social support. Young adults with disabilities have reduced HRQOL compared with peers without disabilities [5–7]. HRQOL may also decrease during the life span [8,9]. This may result in decreasing HRQOL in young adults when they are in the vulnerable transition phase from childhood to adulthood, facing increased demands towards independence and a shift from paediatric to adult healthcare services. Hence, it is important that this phase is well transitioned to be able to participate in society in adult life.

The recommendations for daily physical activity in young adults with CP are similar to those for able-bodied people [10], yet they are less active than their peers [11–13], which make them at risk of declined function [14] and

cardiovascular health problems [15]. Finding the balance between rest, attending physiotherapy and staying active is found to be crucial for young adults with CP [16], thus adapted activities using activity aids, assistive technology, para-professional assistance or modifying the structure of the activity might be a prerequisite for improved participation in everyday life.

People with physical disabilities often attend physiotherapy and there are many approaches within the field of rehabilitation. Goal-directed interventions with functional activities based on activities of daily living (ADL) are among those with the most promising outcomes on improved function and self-care [17]. Outcome measurements in these interventions are often linked to either increased motor function or decreased pain, but evidence of whether actual improvements in physical function influence HRQOL and improved participation in everyday life is scarce. Based on documented benefits of physical activity on psychological well-being and HRQOL [18], we believe that increased HRQOL and participation in everyday life might be a key to sustained activity level after a rehabilitation period. Moreover, increased understanding of how to enhance HRQOL and participation may contribute to reduce disparities concerning this issue between young adults with and without disabilities. The purpose of this study was to gain insight into how goal-directed rehabilitation with adapted functional

Table 1. Questions from the interview guide.

Topic	Questions	Follow-up questions
Rehabilitation and quality of life	How did the intensive rehabilitation influence your HRQOL?	How did the rehabilitation program influence your daily activities? - During the 6 weeks of rehabilitation - After the rehabilitation program
Participation and rehabilitation	How did the intensive rehabilitation influence your participation?	- In leisure time - At school/work - With family and friends

activities in a group setting influenced HRQOL and participation in everyday life for young adults with disabilities of neurological origin.

Research setting, description of the rehabilitation program

The rehabilitation program was carried out at a private outpatient clinic in a large city in Norway and led by two physiotherapists. A total of 15 participants started in the program, and 13 completed the whole period of 6 weeks. The participants were offered transport to and from the training sessions. Participation was free of charge, and there were no adverse events during the training session. The intensity of the intervention was high, with three sessions of 2 h each week for 6 weeks, thus quite time-consuming. Functional training, progressive strength training and cardio-training characterized the intervention.

Due to the diversity among the participants regarding functional and cognitive level, as well as their different personal goals, an individual exercise program for each participant was made. However, group activities or exercises performed in pairs, were aimed for whenever possible. Max strength training with 4×4 repetitions was used for the larger muscle groups with exercises, such as bench press, leg press and lateral pull-down in machines. Both 4×4 interval training and continuous endurance exercise was preformed either on a treadmill, a hand cycle or outdoor running/propelling a wheelchair uphill.

Functional training was related to the participant's goals. Forcing curbs and controlling equilibrium of wheelchair, independent transfer (i.e. floor to chair, sit to stand, chair to wheelchair), climbing stairs, gait training on different surfaces, were tasks included in the individual exercise programs.

Fine motor skills and grip strength were also practiced in functional activities (i.e. opening jars, tie shoelaces, picking up coins from a table, grab and release different objects, pour water from a mug into a cup, walking while balancing object in hand).

The activities were adapted to the individuals by using wheelchair accessible machines and equipment, gloves to provide a better grip on weights, straps on chest during bench press providing increased stability and support and weight supported walking using harness and lift. Adaptions were also made to the participant's day-to-day condition.

Materials and methods

To gain insight into the experienced HRQOL and participation, semi-structured qualitative interviews with six young

adults with physical disabilities were utilized. All the 13 young adults who completed the rehabilitation program were orally invited to participate in the qualitative study by the staff at the outpatient clinic. Six young adults accepted to participate. One focus group ($n = 4$) followed by two individual interviews were conducted. The eligibility criteria were young adults between 13–26 years with a physical disability of neurological origin, cognitively well enough to participate in an interview, fluent Norwegian speakers and experience of attending a group-based goal-directed rehabilitation program within the last 12 months.

The first author KMT conducted all interviews at the rehabilitation centre where the participants had undertaken the intervention. Duration was 45–75 min. The second author, KA participated both as an observer by taking notes and as a co-facilitator by adding follow-up questions during the individual interviews and the focus group. A semi-structured interview guide with open-ended questions was utilized as shown in Table 1. Interviews began with a short explanation of the process of qualitative interview, our interest in the experiences of the participants and the importance of confidentiality. Specific group rules or contracts were not given other than a repetition of the information in the informed consent. No deliberate facilitation styles were used, but the interviewer adapted the conversation to the participants' age and jargon in order to avoid a formal and artificial setting. We had a precognition that the term HRQOL would seem unfamiliar to the young adults, as this specific term is not commonly used in their everyday language. Thus, time was spent on how the young adults perceived the topic by warm-up questions such as "what does quality of life mean to you?" and "what impact does health have on your quality of life?" The young adults were then encouraged to explain to what extent the group rehabilitation influenced their HRQOL and participation in activities of their everyday life.

The interviews were digitally recorded and analyzed according to systematic text condensation (STC) as described by Malterud [19]. STC is inspired by Giorgi's phenomenological analysis [20] and offers a pragmatic approach for thematic cross-case analysis. The method is suitable for novice researchers and is often used within medical research. The analysis consisted of four steps (i) Transcription of audio-files, getting an overall impression of the raw data and sorting out prominent themes. (ii) Identifying meaning units, representing different experiences of how rehabilitation influences HRQOL and participation. These meaning units are fragments of about five to ten sentences from the text. (iii) Coding meaning units, de-contextualization and construction of artefacts, thus providing more condensed data material. (iv) Synthesis of findings from each code group to generalize

Table 2. Emerging themes from the data analysis.

Health-related quality of life (HRQOL)	Participation and HRQOL
Favourable links between the rehabilitation program and HRQOL and activities of daily living <ul style="list-style-type: none"> • Sport skills, mastery • Individual activities, increased independence • Social settings, increased function • General health – positive changes Intensive rehabilitation – a double-edged sword <ul style="list-style-type: none"> • Increased energy or fatigue 	Importance of social participation for HRQOL <ul style="list-style-type: none"> • Increased motivation for maximising effort during training • Gym as an important area for social participation A favourable link between the rehabilitation program and social participation <ul style="list-style-type: none"> • Achieving physical functioning influence the opportunity to participate

descriptions and content followed by illuminating quotes. Both KMT and KA transcribed and analyzed the interviews, interpreted the data and discussed until a consensus was reached. The third author, RJ contributed to the study design and manuscript. All authors read and approved the final manuscript.

The Regional Committee for Medical and Health Research Ethics reviewed the application and considered the study not regulated by the Health Research Act (application no: 2013/2356/REK south-east D). Informed consent was obtained. For participants under the age of 18, both parents and the participant signed the informed consent.

Results

The participants were aged between 13 and 26 years old, two males and four females. Two participants took part in individual interviews, as one was unable to be present at the date of the focus group, and one participant felt uncomfortable talking in a group due to speech difficulties. One participant had an acquired brain injury; the others had either CP or spina bifida. Some of the participants had mild intellectual challenges. Three individuals were wheelchair users, two lived in independent housing (one with a cohabitant), and the others lived with their parents. Participating in an interview was a new experience for most of the young adults, who seemed a little tense during the first few questions. Nevertheless, as we wrapped up the session, they remarked that this novel experience had been positive.

From the analyses of the perceived influence of the rehabilitation on HRQOL and participation in everyday lives of the young adults, four themes emerged (see Table 2). The content of these themes are further elaborated below.

Favourable links between the rehabilitation program and HRQOL and activities of daily living

Four important benefits were mentioned: the influence on sports performance, the influence on individual activities of daily life, activities in social settings and on their general health. The rehabilitation program helped the participants to achieve goals related to their sports activities, such as weightlifting, wheelchair basketball and climbing. One girl told about the overwhelming experience during a national championship where she beat her personal best in bench press:

A lot of people were watching, and I felt the nerves coming, but it also made me eager to do it. Afterwards I felt great

The focus on improving skills in activities of daily living made physical barriers in everyday life less challenging. Improved wheelchair mobility, experiencing better sitting balance, eating and drinking independently, and riding a bike uphill were mentioned as positive outcomes by the participants. Achieving a weight loss goal resulted in a feeling of ease during walking, supplemented by more toned muscles. The intervention also had a positive outcome in relation to participation in their social life. For one of the participants, being able to visit friends and family was an important aspect of HRQOL. After the rehabilitation period, she experienced both increased gait function and improved speech ability, which undoubtedly was beneficial in social activities.

The rehabilitation has made it easier for me to speak, and that makes me very happy and satisfied

The participants' general health status improved after the intervention. Increased energy, better sleep, motivation for activity, and sense of joy in movement were mentioned. By successfully completing an exercise program they considered to be demanding and ambitious, a sense of pride in their achievements occurred. One of the participants had been absent from her studies for a period, and explained that her life was not busy at the moment, but that it would soon change:

If you sit in front of the computer, you don't mind whether you are fit or not. But the rehabilitation gave me a lot of energy, which will be positive when I return to my studies.

Intensive rehabilitation – a double-edged sword

The intervention was both demanding and time-consuming, and the outcome of increased energy or fatigue varied. Some participants felt a clear improvement, while others felt exhausted and tired. Nevertheless, the positive outcome of the rehabilitation, more than made up for the strain and fatigue. Tiredness could not solely be linked to the rehabilitation, but was also a result of stress and hard days at school.

Even if I'm tired at the beginning, I just go ahead with my exercise, and usually my mood blooms. But if I'm extra tired, it just continues, and I find myself in a vicious circle of fatigue.

Although the intervention had been time-consuming, a lack of time with friends or family was not experienced. Participants who were still attending school did not lag behind, and experienced a positive attitude towards the intervention from their teachers. One participant even got a

positive feedback concerning his involvement and participation in class.

He (The teacher) told my mum at the evaluation that I was more attentive and involved in class. That made me glad, and my mum was very pleased.

Importance of social participation for HRQOL

Being part of a social network and shared activities with both family and friends were emphasized in connection with HRQOL. In general, being able to participate in social activities fostered happiness, security, social support and increased energy. Conducting the intervention in a group setting was thus very positive as the participants were both able to practice functional skills that were important for social participation and develop new friendships. The social component with group activities during the intervention entailed motivation for maximizing their effort during training sessions. To be part of a group engendered a feeling of belonging and commitment to attend, and it brought structure to their daily schedule.

I have a gym-appointment with friends, but if they don't show up, I might skip it myself.

A favourable link between the rehabilitation program and social participation

All participants experienced increased fitness after the intervention. For some of them, it impacted upon participation in physical activities. One young boy, who prior to the intervention was afflicted with fatigue and sleep difficulties, experienced a huge gain in his physical fitness. Whereas he usually had to rest after school, he was now able to hang out with friends and play football. It was also much easier to participate in physical education, and he additionally experienced fewer cases of tension in his feet.

I feel much more vigorous and full of energy.

Another participant experienced increased strength in her legs, which was helpful when she went for swimming with her personal assistant. A third young man who had a history of falling experienced improved balance, which helped during hiking with classmates.

Discussion

In this study, we wanted to investigate the influence of a group rehabilitation program on HRQOL and participation in everyday life among young adults with physical disabilities of neurological origin. It is our belief that a qualitative interview is well suited for exploring subjective experience of HRQOL and participation as an outcome after group rehabilitation. The decision to conduct a focus group was based on the assumption that there would be positive dynamic group feedback. Unfortunately, we did not experience this, but rather the opposite situation of inertia and lack of flow in the dialogue. The difficulties in

obtaining a fruitful dialogue could be linked to the heterogeneity of the group due to diversity in age, cognitive function and severity of disability. This further highlights one of the challenges when aiming for social participation in group rehabilitation. Having a small number of participants hampers a good group composition. Yet, the participants call for group interventions should be taken into account.

During the analysis, we acknowledged that HRQOL and participation were intertwined, causing difficulties in separating these terms into codes. As presented in the results, the participants emphasized that being part of a social network and sharing activities with both family and friends were strongly connected with HRQOL. We believe it is plausible that improved physical function enables increased participation, which further promotes increased HRQOL. As far as we know, the reverse influence i.e. increasing HRQOL leading to increased participation is not known, but it could be interesting to elaborate in further studies.

Fatigue was a topic of debate in the group. The intensity of the rehabilitation could be experienced as either exhausting or as a source for increased energy. Prior research indicates that young adults with disabilities have poorer physical fitness and struggle with fatigue [21,22]. One should also emphasize the fact that people with neurological impairments, such as CP, usually have greater energy consumption than peers without disabilities due to their motion deviation and spasticity [23]. This might lead to increased risk of fatigue and could possibly influence HRQOL. Hence, the program should focus on both strategies of energy conservation resulting in efficient locomotion on the one hand, and increased physical fitness on the other. Additionally, pain can be associated with both overuse and inactivity [16], which further complicates the approach for this type of population. On the basis of this knowledge, therapists should preferably have expertise in both neurological impairments and movement analysis.

The term participation is widely used within research, but the construct lacks clarity. Attending a group where all participants to some extent were involved and experienced a sense of belonging in the same activity was an example of how we considered participation should be carried out in our study. This is in line with findings from a systematic review by Imms et al. [24].

An important part of planning a rehabilitation program is to identify barriers for participation, and target functional activities and adaptations in the environment in order to overcome these barriers. This study was planned and conducted by physiotherapists, but barriers for participation are not necessarily caused by physical limitations [25,26]. Thus, one should aim for interdisciplinary programs. Spending time in setting specific goals together with the participant is also essential. Individual goals were set prior to the rehabilitation period, and most of the participants' goals for the rehabilitation were to some extent linked to participation. In retrospect, we should have spent more time discussing and specifying the goalsetting in order to identify barriers and resources for the participants and further targeted them in their rehabilitation.

We would assume that social participation is as important as in able-bodied peers, but wonder if our sample of young adults with physical disabilities put additional emphasis on the social aspect due to an experience of decreased social integration. This would be in line with prior research on how adolescents with impairments participate less in leisure activities with friends than their peers [27]. Nevertheless, the shared attitude towards the importance of social relationships in the group may be seen as a desire for further social integration. This ought to serve as an argument for group rehabilitation with joint exercises, which additionally act as a motivator and may lead to new acquaintances. On the other hand, the diversity in function and goals may entail a greater focus on individual exercises, which challenges the basic premise of the group rehabilitation program.

Three different researchers with different clinical experiences of young adults with disabilities have contributed to the analysis of the data, which we consider a methodological strength. Limitations of the present study must be considered due to the lack of group dynamics during the focus group and to the small sample, which challenge the trustworthiness of the findings. This phenomenon could be a result of the diversity in intellectual functions and maturity related to age. Another possible explanation could be the topic under discussion, which could be sensitive for some of the participants or that the young adults were unaccustomed to speaking their mind in a group setting. We have analyzed data from the young adults who were willing to participate in the study; hence there may be experiences that we have failed to find, since half of the rehabilitation group declined participation in the study. Having a small and diverse sample challenges the transferability of the findings in this study. The findings provide a contribution to clinicians and researchers who are working with rehabilitation programs for young adults with physical disabilities.

Despite some limitations, we gained an increased understanding of the complex feature of participation and HRQOL, and will emphasize user interaction to a larger extent when planning new rehabilitation programs for this population.

Conclusions

Social participation seems to be an important aspect of HRQOL for young adults with physical disabilities. Rehabilitation programs in groups is a positive setting, as motivation and effort seem to increase, yet age and intellectual functioning play a role in this context. Increased physical fitness as an outcome of rehabilitation could successfully be utilized in further social participation. When planning rehabilitation programs for this population, physiotherapists should concentrate on adapted physical activities to avoid increased fatigue, and on joint exercises to give priority to social aspects. The results of the present study indicate that a goal-directed rehabilitation program in a group setting enhance the participation and HRQOL in young adults with

physical disabilities. However, further studies with larger, representative samples are needed to confirm this.

Acknowledgements

We would like to thank all the young adults who participated in this study. We also acknowledge Jannike Rieber, Tove Bergan and Helga Kaale for participation in planning the intervention, Celine Christensen and Torstein Aabrekk-Sørensen for being a co-instructor during the training periods.

Disclosure statement

The authors report no conflicts of interest. The Norwegian Directorate of Health and The Sophie's Minde Foundation funded the study.

Funding

The Norwegian Directorate of Health and The Sophie's Minde Foundation funded the study.

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