

Implementation of physical activity for individuals with severe neurological disability

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ABSTRACT

People with severe neurological disability demonstrate very low levels of physical activity. This may be partly due to physical and/or cognitive impairment, although other factors may contribute. We aimed to investigate and evaluate the processes required for individuals with severe neurological disability to participate in physical activity. This study used a case study design with five participants (three men, two women) who lived in one residential care facility. Each participant and a physiotherapist worked collaboratively to choose, plan and participate in recreational activity over a 12-week timeframe. Data were collected through the physiotherapist's field notes and semi-structured participant interviews. Four participants successfully engaged in their chosen physical activity. The data were analysed inductively for themes and three themes with sub themes were identified. The three themes: 1) There's more than one road to Rome, 2) Benefits, and 3) The ripple effect, highlighted both successful strategies and barriers encountered by participants during this process. This study concluded that it is possible for people with severe neurological disability to be physically active; however, success requires a creative approach to targeting desired and meaningful activities, problem solving through the presenting barriers, and utilisation of available resources.

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INTRODUCTION

The long-term health benefits of regular participation in physical activity (PA) include reducing risk factors, incidence and impact of non-communicable diseases (World Health Organization 2009). Physical activity is defined as "any bodily movement produced by skeletal muscle that results in energy expenditure" (Caspersen et al 1985, p 126). Physical activity levels are decreasing globally (World Health Organization 2010a), and consequently, international, national, and local health policies are now focused on increasing participation in PA for all populations (New Zealand Ministry of Health 2000, World Health Organization 2010b). Despite this focus, the facilitation and implementation of PA for individuals with disability is unclear, especially for individuals who are non-ambulatory and have multiple impairments, for example those with chronic, severe neurological conditions. The World Health Organization (2011a) reports that there are more than one billion people living with disability and 25 million people with neurological disorders worldwide. According to the latest census data, 24% of New Zealanders identified themselves as having a disability (defined as "limited in their ability to carry out every day activities by at least one impairment type") (Statistics New Zealand 2013) and in 2006, 383,500 adults in New Zealand were reported to have a physical disability (Statistics New Zealand 2006).

Individuals with severe neurological disabilities and who require a power wheelchair or an attendant to propel a manual

wheelchair for all mobility are susceptible to complications such as scoliosis, osteoporosis, overuse syndromes, pain, skin breakdown, respiratory infections, arthritis, urinary tract infections, and obesity (Coyle et al 2000, Kinne et al 2004). These complications can initiate a descending cascade of events such as reliance on others for daily cares and reduced self-efficacy (Durstine et al 2000, Gajdosik and Cicirello 2001, Klingbeil et al 2004). Therefore, both the primary condition and concomitant complications have the potential to limit an individual's ability to be physically active.

The recommended amount of PA for an adult is 30 minutes of moderate-intensity activity five days per week and muscular strengthening exercises for the main muscle groups at least two days per week (Garber et al 2011). Individuals with disabilities (Cervantes and Porretta 2010, McGuire et al 2003, Motl et al 2005), including those with severe neurological disability (Motl et al 2005) are less likely to participate in the recommended amounts of PA compared to the general population. This may in part be due to there being fewer opportunities for incidental PA compared to those available for the general population. As an example, if the individual is reliant on a power wheelchair for mobility, choosing to take the stairs is not possible. Furthermore, personal, environmental and societal barriers may account for lower levels of PA participation (Beckerman et al 2010, Damush et al 2007, Rimmer et al 2008). Examples of these are cost (e.g. of suitable transport), an inaccessible environment, regulatory processes, lack of information about opportunities available, attitudes from others, emotional barriers, and lack of suitable

resources. Even though individuals with severe neurological disability may not be able to achieve the recommended levels of PA, participation in some PA still provides benefit (Garber et al 2011). Health professionals can play a role in promoting PA for all individuals, including those with severe, neurological disabilities; however, this role is often not prioritised (Mulligan et al 2011, US Department of Health and Human Services 2009). Facilitation of PA by health professionals (including assistance to overcome the identified barriers) can be limited by funding, prioritisation and resource availability (Mulligan et al 2011, Mulligan 2011), thereby making it challenging to find ways for this population to be physically active.

The aim of this study was to investigate implementation of PA for individuals with severe neurological disability who lived in a residential service. Specific objectives were to: i) identify strategies that enabled PA participation, ii) gain insight into the processes required to minimise barriers and use facilitators, and iii) explore the experiences of individuals with severe neurological disability in participating in PA.

METHODS

This study used a qualitative, bounded, case study methodology as described by Baxter and Jack (2008). The boundaries were defined by i) the study being sited in one residential service situated in a large metropolitan area of New Zealand, ii) at one point in time, and iii) with three researchers (all physiotherapists, one of whom provided the intervention for this study) and individuals with severe neurological disability that necessitated living in residential care. The New Zealand Health and Disability Ethics Committee provided ethical approval (reference number NTY/11/03/032).

Five participants were recruited via consultation with residential service staff members who identified eligible individuals (see Table 1). Nine of the 65 residents met the inclusion criteria and were invited to participate in the study. Inclusion criteria required that they were reliant on a power wheelchair or an attendant to propel their manual wheelchair for mobility, they were able to perform voluntary movement and communicate sufficiently to take part in an interview. One of the members of the research team met each of the nine potential participants individually to explain the study more fully, and of these, five provided informed consent for the study. If a participant had a welfare guardian, the welfare guardian was contacted and provided

Table 1: Study Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
A full time resident at the residential service	Inability to perform any voluntary movement of the limbs or trunk
Reliant on a power wheelchair or attendant to propel their wheelchair for the majority of their mobility	Being medically unwell or unstable
Able to communicate either verbally or via technology in order to participate in interviews	

written informed consent on the participant's behalf following discussion with the participant. Participation was voluntary and did not involve withdrawal from any activities or therapy intervention they were already receiving.

The method is outlined in figure 1. The lead researcher (AB) met with each participant individually to discuss and explore what general and PA interests the participant held. These ideas were then discussed with the research team for suggestions as to how they could be incorporated into PA opportunities for the participant's environment, this being either the immediate environment, that is within the residence, or the broader community environment. We encouraged each participant to make or arrange as many of the required decisions and organisational tasks as he/she was able including encouraging participants to review websites of organisations advertising their PA of interest, and assist in making contact with them.

Each participant engaged in their chosen PA for a period of six weeks, with support from the lead researcher for the first one or two weeks where required. The intent of this timeframe was to provide opportunity to identify and resolve barriers. After the six-week period, the participant chose whether to continue the PA, to stop, or to choose and take on a different PA. At this point, continuing PA was facilitated with support established during the study period, including volunteers and staff from the facility, but was without further input from the research team.

We collected demographic data (including primary diagnosis, comorbidities, and level of function via the Functional Independence Measure and Functional Assessment Measure (FIM+FAM)) from the participants' medical records. The FIM+FAM provided a measure of the functional impact on daily life of the impairments experienced by the participants. We recorded detailed descriptions of the process for each participant via field notes documented by the lead researcher. These were from observations, reflections, discussions and suggestions by the research team and participant as well as feedback from the participants' friends, family and the service's staff. We also undertook individual semi-structured interviews with participants, conducted by the lead researcher at six weeks and again at 12 weeks. These interviews used questions such as "can you tell me the story of you starting your activity?" and "can you tell me about a highlight or difficulty you experienced?" The interviews were audio-recorded and then transcribed verbatim.

We analysed the data for themes as described by Braun and Clarke (2006). The lead researcher read all of the data multiple times then identified and coded similar concepts from the data together to form an initial coding template. This was then reviewed individually by each of the other two researchers and then together as a team to discuss and agree on the final coding template. We then grouped codes together into common themes, with their accompanying sub-themes. We reviewed and revised these themes until we were satisfied that they were an accurate portrayal of our data. The lead researcher presented the themes and subthemes to our participants (who agreed that it reflected their experiences).

RESULTS

The demographics and case report summaries of the five participants are detailed in Table 2 and in the commentaries below. Scores on the FIM+FAM showed a mean of 113.6 (range 96/210 to 141/210), indicating high levels of dependence on others for daily living requirements.

Table 2: Participant Demographics

Participant	Health Condition and Impairments	Secondary impairments, co-morbidities and secondary conditions	Age	Main mode of Mobility	Years since onset	FIM+FAM score
SK (Female)	Stroke resulting in right hemiplegia, dysphagia, poor saliva control, reduced speech intelligibility, and reduced insight, safety awareness and impulsivity.	Multiple previous strokes, asthma, obesity, type II diabetes, osteoarthritis of both knees and chronic obstructive pulmonary disease.	54	Attendant propelled manual wheelchair	2	114/210
CD (Male)	Quadriplegic cerebral palsy resulting in global spasticity and mild cognitive impairment.	Soft tissue contractures, skeletal malformation, bowel cancer resulting in colostomy, obesity	69	Power wheelchair	69	107/210
HR (Male)	Stroke resulting in right hemiplegia, spasticity of right arm and leg and nominal aphasia.	Soft tissue contractures, renal dysfunction, and overweight.	64	Power wheelchair	9	110/210
ZD (Male)	Quadriplegic cerebral palsy resulting in global spasticity.	Soft tissue contractures, skeletal malformation, mild intellectual impairment, restrictive airways disease and renal dysfunction	72	Power wheelchair	72	141/210
PD (Female)	Multiple sclerosis resulting in lower limb paralysis, upper limb muscle weakness, limited trunk control, bladder and bowel dysfunction	Soft tissue contractures, stuttering speech disorder	56	Power wheelchair	18	196/210

All five participants completed the study, with four of the five participants taking part in their chosen PA for the full six weeks. The fifth participant was able to choose and find a preferred PA, and trialled it on one occasion. However, he was unable to find the appropriate support required for him to enable regular attendance at the activity in the six-week timeframe. Three participants continued their PA to the 12-week timeframe and one participant chose to pursue a different form of PA after the first six weeks.

Case report summaries

Participant SK

SK had been living in residential care for the past two years and dreamed of one day returning to living independently in her own home. SK's choice of PA was dance. After we discovered a mixed abilities dance group active in the area, SK attended a public performance of the dance group with the lead researcher (AB), which SK thoroughly enjoyed. AB assisted SK to contact the teacher (via email) and arrange to attend classes. It took a full school term to find a suitable volunteer to assist SK to attend the dance classes. SK's participation in dance has continued into a third term and she has since participated in the dance group's annual public performance.

Participant CD

CD has lived in residential care since he was a child. He has been reliant on a wheelchair for mobility since age eight and now uses a power wheelchair. CD uses a hoist for transfers and requires full assistance for his daily care activities.

CD quickly identified that he wished to have an activity based around animals, specifically dogs. On further discussion, he

suggested that he could invite one of his long-time friends to bring in her dogs so that he could exercise them by throwing a ball. We found, that because of CD's muscle weakness, soft tissue contractures and skeletal malformation in his fingers, wrists, elbows and shoulders, as well as dystonic movement patterns, throwing a ball was challenging, although with practice and hand over hand assistance at first, he improved his throw from a distance of one metre to eight metres over six weeks.

Participant HR

HR resides at one of the service's community homes. He requires one person to assist with a standing transfer and he uses a power wheelchair for all of his mobility. Although HR has a strong connection with his family, they are all living overseas so HR currently has little local social support.

Coincidentally, in the week prior to meeting with him to discuss his interests for PA, AB had organised a volunteer to meet with HR on a weekly basis at his community home, as a social contact because of the lack of family contact. When HR was asked about his interests for PA, he said he had already started playing pétanque (a game similar to bowls) with the volunteer. HR had

been given the pétanque set as a present by his sister, but had not played it until the volunteer started visiting. Therefore, once the opportunity was available, HR had spontaneously initiated PA. In his interviews, he spoke repeatedly about the social aspects that pétanque had afforded him and how important having the social interaction around the PA was to him.

Participant ZD

ZD has lived in residential care since he was a child. He requires full assistance for the majority of his self-care activities but is able to complete his grooming independently once set up with the equipment he requires. ZD uses a hoist for all transfers and a power wheelchair for all mobility. Once in his power wheelchair he is independent. ZD's closest family support (his siblings and their families) live an hour's drive away.

On first meeting ZD to discuss PA he suggested bowls. The research team suggested that a game called boccia could be suitable. This is an adapted form of indoor bowls, played by people with physical disabilities, where different density leather balls are thrown overarm, underarm or pushed down a gutter depending on the person's ability. ZD was very keen to explore this option. A sports and recreation organisation for people with disabilities was able to provide us with information on local sessions and ZD was invited to attend a session. ZD was supported to attend the session by AB, using the service's wheelchair accessible van. ZD enjoyed the game and was keen to attend regularly. Unfortunately, however, we were unsuccessful in finding an appropriate volunteer who would be willing to drive the van and attend the sessions with ZD by the 12 week timeframe. Furthermore, the venue was located 35 kilometres across town, thereby making a taxi fare unaffordable for ZD. This, and the need for a support person to be with him at the boccia, were barriers too great to overcome and ZD did not participate further in boccia.

Participant PD

PD also resides in one of the service's community homes. PD transfers using a sliding board technique with the assistance of two people and uses a power wheelchair for all her mobility. PD often drives in her power wheelchair to the local shops but to go further afield requires a wheelchair accessible vehicle. She has two daughters who live in the same city and visit her often.

PD quickly identified netball as her PA of choice, having enjoyed playing netball when she was younger. AB suggested joining a school team to assist with their drills and practices. PD however suggested that it would be less challenging for transport and its associated costs if other netball players were to come to her residence, given there was a netball hoop on the lawn. PD also suggested that there was another resident in the home who could join in and possibly benefit from playing netball.

We therefore sought to find a volunteer/s willing to come to the home to play with PD and the other resident. After contacting a school with a strong focus on community service, two 17-year old girls volunteered to come each week to complete netball drills and shooting with PD and the other resident. As all volunteers recruited to work in the service have to undergo an interview to deem their suitability for the position and complete a police security check, PD assisted AB with the interview and paperwork and also explained to the volunteers the nature of the support she would require for netball.

Themes

We identified three themes from the data which helped to explain the experiences of all participants; 1) There is more than one road to Rome, 2) Benefits, and 3) The ripple effect.

Theme one – "There's more than one road to Rome".

This theme exhibited that there are many ways to overcoming barriers to PA. Achieving PA by the participants required creativity around identifying and problem solving the barriers that presented and sufficient time to address the barriers. It also required identification of resources and resources already in hand, keeping the activity as simple as possible and being flexible in reaching the goal.

The most frequent barriers we identified were the cost and availability of suitable transport, together with a lack of suitable support persons, such as volunteers, to accompany the participant. We found we had to allow extra time and planning because of this.

No further replies were received from the advertisement for a volunteer... It took longer than a full school term to find an appropriate volunteer." (Researcher's field notes)

We did however discover that using already available professional and social networks assisted us in finding suitable volunteers. One example of this was the recruitment of volunteers through a school network, using the Duke of Edinburgh's award programme (an award programme for youth which requires them to work in four areas including community service.)

We also identified preconceptions and assumptions that presented as potential, rather than real barriers. For example, we had assumed that the cost of attendance at a dance class for SK would be prohibitive because SK was on a disability benefit. This preconception was however challenged firstly by the dance group's director and by SK:

The director of the company explained the cost and stated 'however I wouldn't want this to be a barrier so if [SK] is unable to pay, this can be negotiated'. (Researcher's field notes)

I can pay. I get my benefit every week. It's worth it. (SK 6 week interview)

In addition, the simplest ideas were the ones that were easiest to achieve and maintain. One participant highlighted this in the interview;

What would you suggest to people with disabilities who want to start some physical activity? (Interviewer)

Do something easy at home. (HR 6 week interview)

Flexibility was also required to modify activities to the needs of the individual or to a specific context. This involved challenging our preconceptions and managing the unpredicted events as they arose. For example, the dogs who had 'volunteered' for the ball catching activity would not fetch the ball. Nevertheless, the participant could still throw balls for the dogs.

I think the best bit was throwing the balls at the dogs but the dogs didn't go and chase the ball, they kept running away from the ball. (CD 6 week interview).

Theme two - Benefits

This theme encompassed the physical, social, and emotional benefits that the participants perceived through their experience of being physically active.

SK's dancing prompted her to identify functional goals that now seemed more achievable to her.

"Yes I don't want to sit in the wheelchair anymore. [If you exercise] you get skinny [and] I want to learn how to go to the toilet and get off the toilet." (SK 6 week interview)

For HR, the social benefits, for CD the intellectual stimulation and both CD and SK the emotional benefits were the standout experience.

"What has the best bit been?"

"The company." (HR 12 week interview)

"What have the benefits been?"

"Well it can improve everybody, it can improve everyone as well as myself... gets the old brain something different to think about...it makes you happier." (CD 12 week interview)

"How does dancing make you feel?"

"Good inside [taps chest]... It helped me a lot. I want to live again by myself. I love it, love it, love it." (SK 12 week interview)

Theme three - The ripple effect

This third theme is labelled the ripple effect because it describes the flow on effect of participation and enthusiasm for PA beyond that of the five participants included in this study. Because of the discussions that this entailed with staff and other residents at the facility and its two community houses, attention, participation and enthusiasm towards PA were evident among the staff, management and other residents, resulting in further residents and staff being involved in PA.

Does anyone else join in?

Yeah my neighbour [another resident]. I might see if some of the staff will play it. (PD 6 week interview)

After the first two case studies I noticed staff showing an increase in awareness of PA for residents, and even the managers talking about ways to facilitate PA for other residents using my case studies as examples. (Researcher's field notes)

DISCUSSION

This study demonstrated that despite many barriers, it is possible for individuals with severe neurological disability, who live in residential care, to participate in PA. Success was however dependent upon a number of factors including: choosing PA that is of personal interest to the individual, addressing the barriers, allowing more time and planning than expected, using existing networks and resources, keeping the chosen PA task simple and being creative and flexible. The study also revealed that individuals with severe neurological disability have similar goals, motivations for, and perceive the same benefits of being physically active as anyone in the general population. Furthermore, the facilitation of PA for targeted individuals can have a flow on effect within a residential service such as the one in this study.

Of 64 residents living in the service, only nine met the criteria for inclusion in the study, in that they were reliant on a power wheelchair or an attendant to propel their manual wheelchair for mobility, they were able to perform voluntary movement and communicate sufficiently to take part in an interview. People with complex conditions are frequently excluded from studies investigating participation in PA (Beckerman et al 2010, Haworth and Young 2009). However, we found it reassuring to discover that, with perseverance and a unique and individualised approach, it is nevertheless possible for individuals with severe and complex conditions to participate in and enjoy PA.

In line with the literature on barriers to PA for individuals with neurological disability (Mulligan et al 2012, Rimmer et al 2004, Rimmer 2008, World Health Organization 2011b), we also identified a number of barriers. In our study, lack of access to suitable transport, cost (of transport) and the availability of suitable support personnel were the most challenging to overcome. Four of the five participants required a wheelchair accessible vehicle with a wheelchair hoist and driver to access venues away from their residence. The fifth participant was able to transfer into the front seat of the car but only if her support person was trained in how to assist her to do this and furthermore, knew how to pack away the wheelchair and load it into the car. Like Kirchner et al (2008), we also found that strategies to overcome such barriers need to be individualised and this took more time and effort than we had anticipated.

Literature frequently cites the cost of attendance at recreational programmes as a barrier (Rimmer et al 2004, Rimmer 2008, Warms et al 2007). A review study by Mulligan et al (2012) identified that the cost of accessing suitable venues and recreational programmes was an important barrier from the perspective of people with disabilities. Our study, however, found that it was not so much the cost of attendance at the PA that was the main barrier, but the cost of specialised accessible transport. In addition, we found that cost in itself might be a perceived and not a real barrier. It is therefore possible that health professionals may perceive inaccurate barriers, and that this preconception might in itself become a barrier, thereby resulting in reduced promotion of PA.

In this study personal connections to volunteers from groups that demonstrate a dedication to community service, such as schools or other groups, proved to accelerate the recruitment of volunteers. Using one's own connections therefore seems to be a useful strategy in finding appropriate support. Establishing a "friends of" or a social network group may help to provide a further network to draw upon. Indeed, Gingras (2003) used this type of approach to promote community relationships and build collaborative programming between organisations to maximise and share resources.

Literature and policy (Gingras 2003, New Zealand Ministry of Health 2001, World Health Organization 2011b, Vislie 2003) encourage full integration of individuals with disabilities into society so that they can contribute equally to society (Van de Ven 2005). Although our participants had the choice to leave their place of residence for their PA, interestingly, three chose their own living environment for its familiarity and lack of barriers, specifically transport and cost. This preference fits with a study by Milner and Kelly (2009), also conducted in New Zealand, where individuals with disabilities identified that

they enjoyed the security, comfort, simplicity, and predictability of an environment known to them, where support persons understood their needs.

Our participants recognised the same motivators for PA as a non-disabled population. To this end, they perceived the benefits and motivators of losing weight, achieving physical goals, social interaction and enjoyment. It appears that the reality of the benefits of PA are no different for people with severe neurological disabilities than for the general population. This fits with the American College of Sports Medicine guidelines (Garber et al 2011) that recommend that if people are unable to achieve the recommended levels of PA, they can still gain benefit from lower levels.

The ripple effect from role modelling of our participants becoming physically active led to other residents partaking in PA beyond that of the research study. A study by Heller et al (2002) found that participation in PA for adults with cerebral palsy living in nursing homes was heavily influenced by the caregivers' attitudes towards PA, so that where caregivers had a negative attitude towards PA, then those residents did not participate in PA. This suggests that if staff in residential services are able to observe the benefits of PA for individuals within their care and can learn through modelling experiences how PA can be modified to be achievable, then participation levels of the residents may rise. This concept, however, requires further investigation.

CONCLUSION

This study found that it is possible for people with severe neurological disability to achieve PA but that success requires creativity in targeting desired and meaningful activities, time, problem solving, and the identification of resources. Initiation of PA can initiate the 'ripple effect,' a widening awareness and subsequent participation in PA beyond the original clients. Because PA is important for everyone, including people with severe disability, we therefore suggest that health care providers have a responsibility to be creative and seek ways of implementing and enabling PA for their clients. This study informs individuals with disabilities and their support persons, health care professionals, people who provide PA opportunities, and funders of services for individuals with disabling conditions about ways to achieve health and well-being via physical activity.

KEY POINTS

- It is possible for people with severe neurological disability to become physically active.
- Participation in physical activity by people with severe disability requires creative support from support persons and health care providers, but can nevertheless be achieved for people living in a residential facility.
- Modelling of physical activity participation by some individuals creates a widening awareness and subsequent participation by others.
- Individuals with severe neurological disability, although commonly unable to achieve the recommended level of physical activity for health, are able to gain benefits from participation in physical activity.

PERMISSIONS

The New Zealand Health and Disability Ethics Committee provided ethical approval (reference number NTY/11/03/032) for this study. Participants provided informed consent for the study. If a participant had a welfare guardian, the welfare guardian was contacted and provided written informed consent on the participant's behalf following discussion with the participant.

DISCLOSURES

The lead author is employed by the organisation that funds and manages the residential facility in which participants lived, and received partial financial support from the parent organisation towards completion of her Master of Physiotherapy, which this study was part of. The other two authors report no declarations of interest.

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