Accessing the Community: A Group Intervention to Enhance Community Mobility for Adolescents and Young Adults with Cerebral Palsy

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Key words: neuro-motor disorder, meta-cognitive approach, accessible public transportation, powered mobility, road safety

Abstract

Accessibility to public buildings, transportation and public areas promises easier community integration and fuller participation for wheelchair-users. People with cerebral palsy often have associated disabilities such as difficulties with visual, communication or executive functions that limit their ability to take advantage of these new possibilities. This article represents a practice analysis of a navigation group intervention. It describes its theory-based protocol and its rationale that involves the development of new roles through successful interactions with the environment, among other things. Participants learned and practiced new skills needed for community mobility and developed problem-solving techniques for resolving both foreseeable and unforeseeable hurdles. The intervention emphasized the importance of purposeful transfer of the skills and strategies learned during the group sessions. In addition, group members learned how to make adaptive responses

to the emotional reactions triggered by their interactions with the public. Personal, measurable, short term goals were formulated through the Goal Attainment Scale (GAS). Although the intervention requires significant time and manpower resources, it enabled participants to advance with respect to their chosen goals. Moreover, they expressed eagerness to continue the group and displayed readiness to implement the new skills they acquired.

Introduction

Community mobility enhances inclusion and participation by enabling people to get to where they want or need to go - such as places of work, places of studies or, sites for leisure pursuits - in a normative fashion and as part of the general public. Mobility in the community and the use of public transport require many skills and abilities. These include becoming familiar with road safety rules and following them, orienting oneself and finding bus stops and train stations, planning a route, asking for assistance with the on/off bus ramps, maneuvering amongst passengers and baby prams, making the required payment, and communicating with strangers. Moreover, the use of public transport often requires people to perform a series of actions and procedures within a limited time frame with many people watching and waiting for their turn to get on or off the bus/ train, and so on. These skills may be difficult to perform for people with disabilities, including adolescents and young adults with cerebral palsy (CP), who were the target population for our multi-faceted group intervention.

Recent years have seen the development of much legislation to support the community integration and participation of individuals with disabilities, such as the Equal Rights for Persons with Disabilities Law (1998; 2005), the U.N. Convention on the Rights of Persons with Disabilities (2006), as well as a myriad of laws related to the accessibility of public transportation, and existing/ new public buildings, infrastructures, and services. These laws have drastically increased awareness as well as accessibility for people with disabilities. Their implementation include the addition of bus ramps for wheelchair users to get on and off buses, lowering curbs, and widening aisles and entrances to bus stations and shops, and more (Regulation of Access to Public Transportation, 2003). Unfortunately, adolescents and young adults with CP are often challenged by impairments that go beyond motor control and mobility, thus they must be directly taught the skills necessary to take advantage of these new opportunities.

CP is defined as a 'muscle and movement' disorder resulting from early brain injury (Straub & Obrzut, 2009). However, the extent of the brain

damage within the CP population is can differ significantly, resulting in a heterogeneous group. Individuals with CP often have associated visual, and cognitive impairments, as well as speech impairments due to their poor muscle control (Sgurdardottir & Vik, 2010; Straub & Obrzut, 2009). These associated impairments significantly impede community mobility, as a result of their impact on the effective performance of the necessary underlying skills.

Executive functioning (EF) impairments are also found among individuals with CP (Bodimeade, Whittingham, & Boyd, 2013; Bottcher, 2010; Bottcher, Flachs, & Uldall, 2010; Straub & Obrzut, 2009; White & Christ, 2005). EF is an umbrella term for higher level cognitive skills such as self-regulation, problem solving and organization, which are needed to perform novel and complex goal directed activities (Bodimeade, Whittingham, Lloyd, & Boyd, 2013). EF limitations are well documented in cerebral palsy (White & Christ, 2005; Straub & Obrzut, 2009; Bottcher, 2010; Bottcher, Flachs, & Uldall, 2010; Bodimeade, Whittingham, & Boyd, 2013). These studies have documented that 53% percent of youths with CP exhibit moderate executive dysfunction and 35% exhibit severe executive deficits (Pirila, Van der Meere, Rantanen, Jokiluoma, & Eriksson, 2011). There is sparse literature regarding EF interventions for individuals with CP, thus their efficacy in this population is not well known. However, cognitive and metacognitive strategies for addressing executive dysfunction have proven effective in similar populations, such as adolescents with neurodevelopmental or acquired neurological disorders (Ricco & Gomes, 2013).

Recently, Bottcher (2010) proposed a dynamic interaction-based intervention for individuals with CP, which emphasizes participation and social learning in order to enhance cognitive and executive function development. Bottcher's multifaceted intervention model was implemented in the group intervention described in this article, to assist young adults with CP use public transportation and by that attain greater independence in community mobility.

Description of the Group Intervention

Participants and procedure

A navigation group for 16 to 21year-old special education students was developed at the Ilanot School in Jerusalem, Israel. Participants included 13 students; 77% with CP (spastic or athetoid) and 23% with other neuromotor disabilities. All the participants had limitations in mobility that required their use of powered wheelchairs, either for exclusive outdoor use or for both indoor and

outdoor use. Participants varied as to the extent of their visual, speech and/or executive function difficulties.

The intervention was held in two separate classes, and consisted of a weekly 45 minute sessions throughout the school year. The sessions had a routine format: participants collectively planned an outing, such as to a restaurant, the mall or a film over two consecutive sessions. The level of skills required for the outing progressed from the ability to navigate the immediate neighborhood to taking public transport. The amount of assistance they required also varied from direct supervision and physical help to distant supervision without any assistance. The following week the session time was increased from 45 minutes to at least 2 hours, and the group was accompanied staff members (one staff member per student). During most of the outings, the staff supervised, cued, or provided help at the minimum degree possible. In addition, the outings were videotaped whenever possible. During the final monthly group meeting, the students viewed the video footage of the outings, and analyzed their successes, difficulties and their use of strategies they also discuss how they felt. This sometimes required more than just one session.

The group facilitators were an occupational therapist and a physiotherapist or special education teacher with expertise in working with adolescents with CP. Classroom aides were present in the discussions and helped students in the outings. Often other staff members also joined the outings, resulting in a staff to student ratio of 1:1 or 1:2.

The group intervention's model and approaches

Conceptually, the group was based on the Model of Competence (Rousseau, Potvin, Dutil, & Falt, 2002), which proposes that a positive interaction between a person (mind and body) and his/her environments (cultural, social and physical) will be interpreted as success. Success will then promote the assumption of roles that lead to competency. In contrast, a negative interaction will lead to role rejection, and increased disability. Environmental factors within all of a person's various environments must be considered to fully understand his/her performance limitations and increase his/her participation (Kjersti, Lilja, & Nygard, 2007; Roy, Rousseau, Allard, Feldman, & Majnemer, 2008).

The use of this model was employed by the group facilitators to support members' experience of positive interactions in community mobility and to take on a new role as consumers of public transportation and community services alongside the rest of the general public. The intervention focused on three major areas: learning new skills, using metacognitive strategies, and coping with emotional responses. of public transportation and community

services alongside the rest of the general public. In order to achieve this positive interaction the intervention focused on three major areas: learning new skills, using metacognitive strategies, and coping with emotional responses.

Learning new skills. As the students had no prior experience using public transportation, their learning of new functional skills was important. This aspect of the intervention was guided by social, cognitive and constructivist theories of learning (Helfrich, 2014). In accordance with these theories the students acquired new skills through observing other peers within the group, as well as staff members and the 'strangers' around them. The group itself provided valuable opportunities for this learning. The participants actively combined the discovery and creation of their own knowledge, with observing, gathering information and using cognitive processes such as critical thinking, and examined potential positive and negative outcomes to decide how best to achieve their goals. For example, if their sub-goal had been to go to a certain coffee shop from the bus stop, they would consult with the staff members, role play the situation, and watch the video footage of themselves and their peers to learn what their various options had been. This stage of learning was crucial, and given the participants' lack of experience, it required a substantial amount of time.

Metacognitive strategies. The metacognitive approach was another major component of the intervention. As described earlier, difficulties in EF skills significantly affected the participants' ability to achieve their goals even after the new skills had been learned. The metacognitive approach comprises teaching systematic organization and problem solving (Riccio & Gomes, 2013). This approach has been shown to be effective with adolescents (Young & Amarasinge, 2010) as well as in in group settings (Ownsworth, Fleming, Shum, Kuipers, & Strong, 2008), and has shown promise in enhancing treatment outcomes for individuals with CP (Bottcher, 2010). An important aspect of this group intervention was the teaching of global and specific strategies to improve task performance, such as breaking down tasks into smaller steps in order to guide goal-directed behavior (Missiuna, Mandrich, Polatajko, & Malloy-Miller, 2001).

Another aspect of EF that was emphasized was problem solving skills. Students had to come up with different options to circumvent unexpected barriers, and then choose the best possible option. The challenges that students encountered during group outings varied greatly in complexity. For example, on one occasion, a student asked a person on the bus to pass his/her bus card forward for the driver's inspection, and this person

did not understand what the member was asking him to do. In addition, sometimes a bus did not stop at the bus stop as anticipated. Some of the problems were quite common and "ready-made solutions" could be implemented; such as when a barrier obstructed the students' path or when other people did not understand their speech. On some occasions, the problems encountered challenged the students and their accompanying staff; such as when a bus didn't pull up close enough to the curb to safely use the bus ramp.

Most outings were videotaped so that they could later be reviewed. Reviewing the tapes enabled participants to discuss strategies that were or were not used, and the successes and difficulties they had encountered. In this manner, participants were able to plan ahead and prepare themselves for the next outing and its subsequent challenges. Practice in this area helped the students realize that each of the problems they encountered could be solved in a variety of ways. Moreover, by monitoring their performance via the video tapes, the participants gained increased self-confidence and began to perceive themselves as being capable of achieving the goals they set for themselves, despite the inevitable challenges they would encounter.

Emotional responses. Many emotional issues were raised as the students interacted with the population within the general public instead of the sheltered environment of special education. Their own reaction to the manner in which the public related to them and their feeling of being different, their attitude towards their disability and more. In order to deal with these emotions and with their consequent responses, cognitive behavioral processing was implemented. This approach analyzes situations as events that evoked emotions and resulted in actions within a particular context of belief. The students discovered how their underlying beliefs could be adaptive or maladaptive, leading to positive or negative emotional and behavioral responses to the events. The use of this approach enabled them to see other options for coping with emotionally tense situations. According to Bruce and Borg's (1999) description of this approach, cognitive function mediates behavior and affect and therefore by modifying the maladaptive thoughts one can alter behaviors that limit functioning.

Cognitive behavioral approaches have been recommended for occupational therapy intervention for adolescents with chronic diseases in order to help them change the cognitive processes and maladaptive habits that affect their behavior (Brown, Delisle, Gagnon, & Sauve, 2001). With respect to the current group, students who believed they should promote integration had patience and did not get frustrated with people who had difficulty understanding what they were

trying to say, they simply repeated themselves until they were understood. On the other hand, in the same situation, students who were embarrassed by their slurred speech often felt anger or avoided talking to strangers, even when this prevented them from achieving their personal goal. Thus, by discussing their underlying beliefs and recognizing which were adaptive and which were maladaptive, the students gained more control over their responses to events experienced. For example learning to talk to people they don't know and who don't understand their slurred speech, despite the comments and reactions they receive.

The group members differed in cognitive abilities and the depth of analyses varied accordingly, although emotional maturity and understanding the feelings of others did not seem to correlate with general cognitive levels. Often the young adults at lower cognitive levels were too absorbed in the complexity of performing their own tasks to be aware of others' reactions. Consequently they were not as disturbed by the general public's response to them as other members were. It is important to note that the staff was not specifically trained in cognitive behavioral treatment, they (rather they used it) as part of the holistic approach. A crucial part of these three spheres of intervention (learning, metacognition and emotions) is to facilitate the explicit transfer of the newly learned skills. According to the multi-context approach (Toglia, 2010), skills must be practiced in slightly different environments or with slight variations (near transfer), followed by practice in more disparate situations (very far transfer), to actively teach the transfer of the skills. For example, the students first learned to cross the street at the crosswalk by the school that has two way traffic, then at other crosswalks with two way traffic (close transfer) and later at streets with crosswalks and four way traffic as well as streets with traffic lights (very far transfers). The staff was often surprised to realize that few skills were transferred to new but similar situations, if the skill transfer wasn't worked on directly and explicitly. With respect to the current group intervention, a conscious, methodological approach was implemented to highlight transfer of skills and bring the transfer itself to the foreground. In accordance to the multi-context approach (Toglia, 2010), the training gradually progressed from near transfers to far transfers, in order to allow the newly acquired skills to be implemented in a variety of situations. This was done with new skills as well as with metacognitive strategies. For example, in order to highlight the transfer of metacognitive strategies the same wording was always used to break tasks down into steps. Another example of explicit transfer used was to emphasize how the students' adaptive and maladaptive beliefs

affected behavior in different areas. This part of the intervention required a significant investment in time and effort for both the staff and the group members. This group ran weekly for the duration of the school year and often continued on for a number of consecutive years.

This trifold approach of learning, metacognitive strategy use and emotional analysis guided the intervention. It allowed the students to practice and refine the skills needed for community mobility through the performance of meaningful activities and personal goals that represented a core element of the group.

Specific goals. Individual as well as group goals were jointly formed with the students at the start of the intervention. The Goal Attainment Scale (GAS) was used to formulate functional and measurable short-term goals (McDougall & Wright, 2009). (See an example of a goal chosen by one of the participants in Table 1). The goals varied greatly according to which outcomes were important to the students, and according to their abilities and potential. For M. (below) the ability to organize a leisure activity was paramount. Other students chose goals that included taking public transport (with varying levels of independence), and/or shopping in a local store/ restaurant.

Table 1

M's Individual Goal - According to GAS

+2	Improvement greatly above the expected	M. will organize an outing after school hours
+1	Improvement above the expected	M. will organize the outing with supervision only
0	Goal	M. will organize an outing to the local coffee shop, with general, non-specific cues from a staff member
-1	Slight improvement	M will be able to plan each subtask of an outing, if a staff member helps M break the goal down into smaller steps
-2	Baseline	M needs direct verbal cueing to break down goal into the steps required and to plan each subtask

These specific goals helped the students analyze what tasks/skills they do well, which ones they wish to improve, and allowed them to monitor their progress. The long duration of the group intervention highlighted the important contribution of the GAS. Towards the middle of the year, the students often expressed surprise when they read their baseline level. Through their GAS charts, they were able to discern and appreciate the improvements they'd made. Participants demonstrated functional improvement (as measured by the GAS), expressed greater confidence during their personal interviews, and conveyed their readiness to continue using public services and transportation, whether with the assistance of and aide or independently, according to their abilities.

Discussion

The goal of this group intervention was to promote community mobility among adolescents and young adults with CP, including the use of accessible public transportation. The intervention was based on theories from occupational therapy, as well as from cognitive and behavioral disciplines, in order to address the numerous areas of difficulties found in the target population, through the use of a holistic approach. This group approach was thought to be more effective than individual intervention, since the group members were afforded the opportunity to learn new skills that included problem solving and metacognitive skills, both directly and from their peers. Moreover, the students benefited from receiving feedback from the "outside" world. Having fun was another important element of this intervention, as the participants achieved learning while going on pleasurable outings, such as going for pizza together, in contrast to learning more academic subjects within the school framework (i.e., geography). This element served to contribute to the group members' motivation.

The staff also gained insight into the complex difficulties that the students must cope with. These difficulties included the complexity of getting on and off a public bus for the wheelchair-dependent population and the intricate executive skills required in navigating and in using public transportation. moreover, they learned to better appreciate the students' need for more than the usual amount of time to perform tasks independently and without interference, due to their slow reaction times. The group intervention also required generous allotments of time and 'one on one' manpower for the outings, which must be considered when planning this kind of intervention.

Community mobility for people with CP and associated disabilities, is not always easily achieved despite

recent laws granting accessibility to their environments. Though the demands of the group are high, the holistic approach described in this paper offers a method to help them improve in the required skills and increase their community mobility. This is a significant goal for the participants, as it allows them to travel alongside the general public and enjoy community services such as shops and restaurants as an equalmember of society, thereby increasing their participation and inclusion in the community. A comparison of children with CP and their typically developing peers according to the International Classification of Function, indicates that the largest differences between them are seen in participation in community life and recreation (Calley et al., 2012) therefore emphasizing the importance of addressing these issues.

Engel-Yeger, Jarus, Anaby, and Law (2009) studied the participation patterns of 52 adolescents (ages 12-16), 22 of whom had CP and attended special needs school, verses 30 typically developing children. They found that youths with CP participate in fewer activities than their peers, and less often, though their level of enjoyment was the same. They also found that the adolescents with CP participated in more activities at home or in an adapted environment than the typically developing youths, who participated in activities with their friends. This is in accordance with findings by Stevenson, Pharoah, and Stevenson (1997) who examined the transition to adulthood of youths and young adults with CP. They found youths with CP to be more socially isolated than a matched control of typical youths, and that their isolation increases after they finish school. The authors stressed the need for a greater focus on this problem and highlighted the need for proactive planning while the youths were still in school, to increase their level of social activity.

In another study of 203 youths with CP (aged 12.9-19.8 years), Livingston, Stewart, Rosenbaum, and Russell (2011) found that the teens felt that active leisure and mobility activities were the types of activities that were the most important for them to participate in. The authors suggested that intervention should be aimed at these areas, teaching self-advocacy, building personal skills, reducing environmental barriers (physical, social, cultural, etc.) and increasing environmental supports. They also stressed the importance of empowering the youths' identities through participation in meaningful activities. The group intervention described above matches these recommendations: 1. It relates to all of the students' environments; 2. Is based on activities chosen by the youths, and 3. Incorporates approaches to provide members with the skills they need through learning, the use of metacognition strategies and the use of cognitive behavioral techniques to enhance emotional

awareness. In this manner, we hope that this group intervention will promote the integration of youths with CP, reduce their level of social isolation and extend the boundaries of their participation beyond the comfortable walls of their homes and special needs facilities to the larger community in which they live.

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