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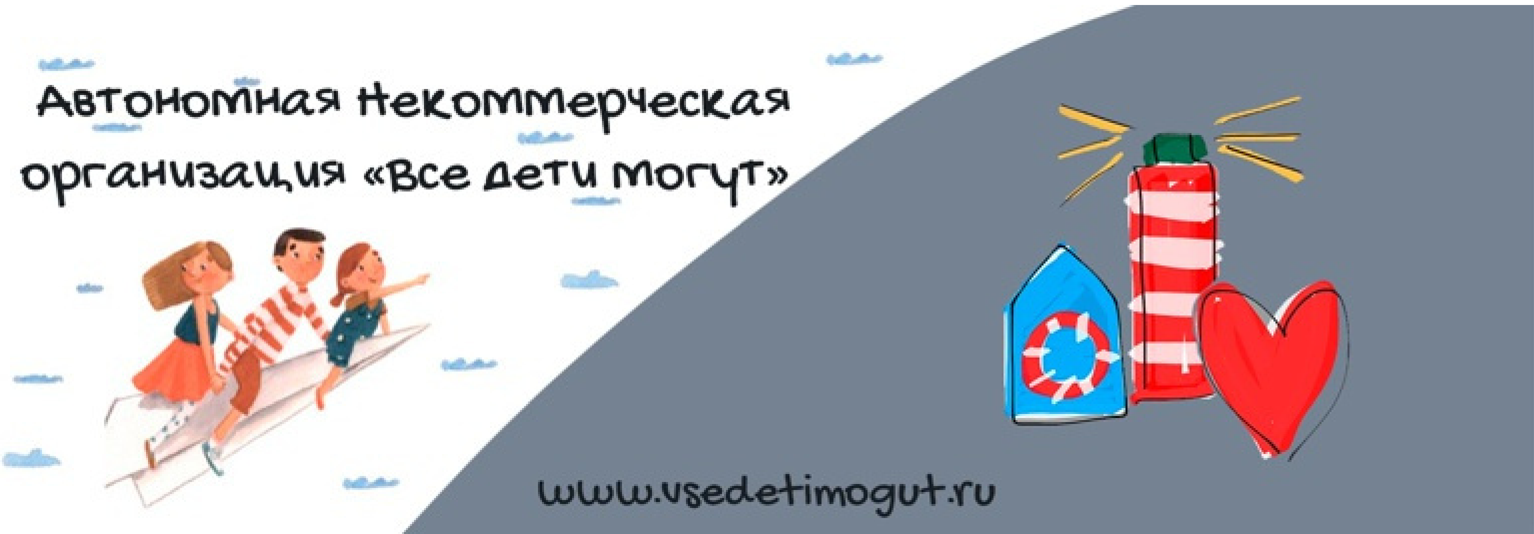

ASSISTIVE TECHNOLOGY FOR PERSONS WITH PHYSICAL DISABILITIES

Evaluation and Outcomes

Revalidatie hulpmiddelen: het meten van uitkomsten

door

Patricia J. Rigby

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Revalidatie hulpmiddelen: het meten van uitkomsten
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Prof. dr. C. Macarthur, University of Toronto

Now I look beyond what I can't do and focus on what I CAN.

Robert M. Hensel

Contents

1
Chapter

Introduction

Patricia Rigby

Introduction

Rehabilitation for persons with physical disabilities has evolved over the past two decades. These changes have influenced how rehabilitation services are delivered, and how rehabilitation disciplines approach research and inquiry. This chapter explores the paradigm shifts, current trends in rehabilitation practice and research, and how these have influenced the evaluation of assistive technology devices. The research included in this thesis spans a decade of study of the impact of assistive technologies on functional outcomes that are both clinically relevant, and meaningful to persons with physical disabilities.

Paradigm shift in rehabilitation for persons with a physical disability

The International Classification of Functioning, Disability, and Health (ICF) (1) was developed in response to a global shift in views about disability and health, and provides a unifying conceptual framework for rehabilitation practice and research (2-4). The ICF was officially endorsed by all WHO Member States in May 2001 (resolution WHA 54.21) as the international standard to describe and measure health and disability. By using this framework, the health and wellbeing of persons with physical disabilities can be understood universally.

The ICF framework reflects the shift from a biomedical understanding of disability and handicap, to a biopsychosocial perspective. Within the biomedical perspective, the person's impairment was viewed as the cause of disability, and researchers and clinicians focused on finding the cause and a cure for the impairment (5). As a result, rehabilitation focused on treating the constraints imposed by the impairments of the disabling condition, with hopes of reducing or 'fixing' the impairment (6, 7). The biopsychosocial perspective arose from the disability rights movement of the 20th century, as well as the social model of disability. People with disabilities now expect to have choices and control in their daily lives and to be fully integrated into society (8, 9). The biopsychosocial perspective incorporates a social construction of disability in which attitudinal and other environmental factors play a defining role. The focus is on the experiences of disability and health within one's daily life (1).

Rehabilitation is considered a critical process for enabling persons with disabilities to achieve autonomy and social inclusion. The primary goal for rehabilitation, based on the ICF, is to optimize functioning of people who experience disability in their daily lives (3, 4). According to the ICF, function is the outcome of a dynamic interaction between body structure and function (physiological and psychological), personal factors that describe a person's life and living conditions, and environmental factors that make up the person's physical, social, and attitudinal environment. It is the interplay of these factors that determines the extent to which a person can engage in daily activities and participate in life situations within society. Disability occurs when the person has impaired functioning and experiences activity limitations and restrictions to participation in daily life (2). In the ICF model, disability can be modified by personal and environmental factors.

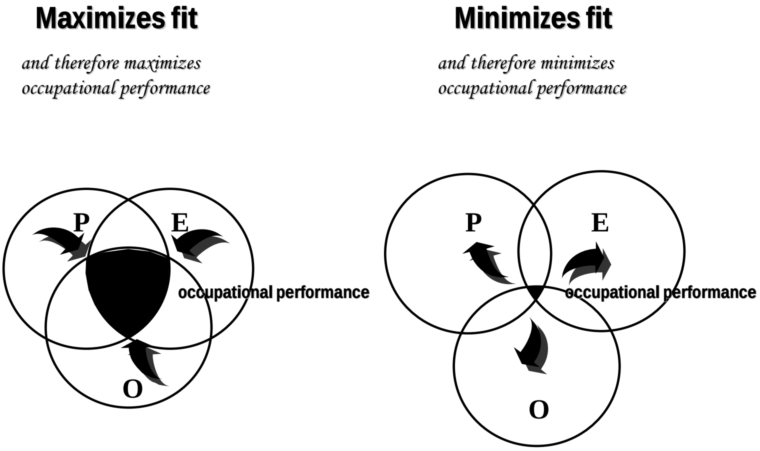
In rehabilitation settings for children, youth and adults, the ICF, and the recently introduced ICF for Children and Youth (ICF-CY) (10) can be used to frame assessment, goal setting and treatment planning, and the evaluation of meaningful outcomes (11-15). Rehabilitation therapists use a variety of interventions to improve activity levels and enable participation in life situations. Interventions that focus on the actual performance context for an individual (within the home, work, school, or the community setting) can be directed at the person or the environment. Interventions can improve the individual's personal skills and abilities, or use environmental modification (either by eliminating environmental barriers or by using environmental facilitators) to enable performance of actions and tasks in daily living (11, 12, 16).

The Person-Environment-Occupation Model

Occupational therapists are key members of the rehabilitation team. In contemporary occupational therapy practice the goals for intervention are more clearly focused on enabling engagement in and performance of occupations that have meaning and purpose in a person's life (16, 17). Occupations are comprised of the actions, tasks and activities that people do in daily life, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of the community (productivity) (18, p.34). Occupations are considered central to a person's identity (19), are defined by roles and responsibilities (16), and are an important determinant of health and well-being (19-21). These views about occupation and the focus for occupational therapy practice are compatible with the definitions for activity and participation, and the goals for rehabilitation as described in the ICF.

Rigby together with Law and colleagues developed the Person-Environment Occupation (PEO) model in the mid-1990's to demonstrate the dynamic nature of occupational performance (16). This model was adopted by the Canadian Association of Occupational Therapists for their guidelines for client-centred occupational therapy (OT) practice (18), and is widely used (11, 20, 22-25). Occupational performance is defined as the outcome of the transactional relationship experienced by persons with their occupations, and with the environments in which they live, work and play, and is the outcome of interest for OT practice (16). A simple Venn diagram, as shown in Figure 1, illustrates the person-environment-occupation relationship as three overlapping circles. Occupational performance, the doing of occupation, is depicted as the goodness of PEO fit or congruence. Increasing the overlap of the circles to improve the PEO fit will improve the quality of a person's experience, with regards to their level of satisfaction and their occupational performance (25).

Figure 1: PEO Model – showing the goodness of person-environment-occupation (PEO) fit or congruence



One of the major contributions that the PEO model has made to OT practice, and to rehabilitation in general, was to explicitly articulate a broadened view of possible interventions. For example, OTs no longer see environmental interventions as a last resort. OTs now make environmental modifications, use environmental resources, and examine how the occupation can be adapted to enable a person with a disability to perform occupations of their choice, rather than focusing all efforts on trying to rehabilitate and fix impairments, as was the focus with the biomedical model (7, 23, 26). Assistive technologies are considered environmental resources and are widely prescribed by OT's to improve the occupational performance of person's with disabilities (27).

The PEO model is compatible with the ICF, and both theoretical perspectives provide the conceptual underpinnings for the research conducted for this thesis.

Adoption of client-centred and family-centred models of service delivery

The adoption of a client and family-centred approach to care has had an enormous influence on rehabilitation practice. In client-centred practice, clients and families are actively involved in managing their own or their family member’s care. Rehabilitation occurs in partnership with service providers. Clients and families actively participate in decision-making and establishing priorities for their rehabilitation, and their perspective is sought during evaluation of outcomes of rehabilitation services (28, 29). Client and family-centred care is competency enhancing rather than weakness focused (30); values that are shared by the ICF and the PEO model.

Research has shown that client and family-centred practice has a positive impact on the motivation of persons undergoing rehabilitation (31, 32) and on rehabilitation outcomes (29, 33, 34). The shift to client and family-centred care has important implications for the evaluation of the outcomes associated with rehabilitation interventions. Rehabilitation researchers and service providers have become increasingly aware of the need to measure rehabilitation outcomes that are of relevance and importance to clients and their families, within their daily lives (28, 35-37). In client-centred rehabilitation, the evaluation of outcomes must incorporate the perspective and expectations of the client, not just those of the rehabilitation professionals.

Parallel shifts in assistive technology development and interventions using assistive devices

The role of assistive technology in rehabilitation

Assistive technologies are devices or products that are designed to enhance the functional capabilities of persons with disabilities, (27, 38) and fall into the products and technology category within the environmental factors domain of the ICF (1). While some authors broadly define assistive technology (39, 40), for the purposes of this thesis the focus is on assistive technology devices (ATDs) that are directly used by individuals with a physical disability. Rehabilitation therapists routinely prescribe ATDs to enable persons with disabilities to engage in daily activities, to gain greater autonomy in doing activities, and to participate in life situations within their home, school, work and community environments (27, 38, 41).

Typically devices are prescribed to meet specific activity goals of clients and to achieve a goodness of fit between the person, their desired activity and the environments in which they are living (27, 41-43). Many assistive devices are designed to reduce the limitations resulting from impairments and illness, and provide alternative or adaptive ways to do specific activities. For example, wheelchairs enable persons with a mobility impairment to move around their home and community, a bath bench allows a person to transfer into a tub sitting rather than standing, and electronic writing aids provide users with an alternative way to produce written work. ATDs are prescribed to improve participation in home and community activities, and by doing so are expected to enhance quality of life (27, 44).

Widespread availability and usage of assistive technology

Assistive technology has undergone dramatic innovation over the past 20 years, and the availability and quality of the technology has greatly improved (27, 39, 44-46). ATDs are widely used by persons with disabilities. For example, in 2006, nearly two-thirds of the 2.7 million Canadians with a disability who were 15 years and over used ATDs to help them perform one or more daily activity (47). In the mid 1990s in the US there were 1.6 million wheelchair users living in the community (48). However, the contributions of assistive technology to rehabilitation outcomes are not well understood (45, 49, 50).

The need for assistive technology outcomes research

In parallel with the advances in assistive technology development and availability, assistive technology researchers have identified the need for assistive technology outcomes research (39, 45, 49, 51). There are good reasons to evaluate the outcomes of ATD interventions. In evidence-based rehabilitation practice there is the commitment to use and integrate the best available knowledge and evidence into the clinical reasoning process to guide assessment and intervention, and to predict probable outcomes (39, 52, 53). In other words, rehabilitation therapists need to know what works, how well it works, and for whom it will work. Rehabilitation clients, their families and their caregivers need advice about what will work best for them within the context of their daily life (53, 54). Evaluation of outcomes is also essential when new technologies are being developed to ensure that they function as they are designed to do and meet the needs and expectations of clients.

There is a pressing need for evidence to substantiate and justify the benefits of rehabilitation interventions, particularly in the current economic climate when healthcare resources are rationed. This is particularly important when many assistive devices are costly and there is consumer demand that governments and other payers cover the costs. In Ontario, Canada, for example, the provincial government spent $214 million (CAD) in 2003 to subsidize the cost of assistive devices for nearly 200,000 people with disabilities (55). Policy-makers and payers require evidence to support the effectiveness of assistive technology interventions (45, 50).

The goal for assistive technology outcomes research

An important goal of AT outcomes research is to measure the changes that are enabled or produced by ATDs in the lives of users. The changes may range from improvements in abilities, performance in daily activities, participation levels, and quality of life. These changes may, in turn, reduce the need for caregiver assistance and other environmental resources (39, 41, 45, 56).

Identifying and selecting appropriate outcome measures for evaluating assistive technology

Measuring the outcomes of assistive technology interventions poses numerous challenges to therapists and rehabilitation researchers alike. Rust and Smith (57) examined the scoring methods of 100 widely used health and rehabilitation outcome measures and found that most fail to capture the impact of assistive devices on functional outcomes, including activity performance and quality of life. They found that 30% of the measures ignore ATDs, 40% lower the score when ATDs are used, and 22% only allow the ATD for the highest score. They conclude that this inconsistent evaluation of the influence of ATD generates inaccurate rehabilitation outcomes and hinders understanding of the role of ATD in enabling a user’s abilities, activity performance and participation.

Lenker and colleagues (50) examined 82 ATD outcome studies published from 1980 to 2001 and found that most of the measures used in these studies had been developed specifically for that study and lacked evidence of validity and reliability. The samples included in these studies were heterogeneous with respect to age, disabling conditions and type of ATD used. This hampered the interpretation of outcomes and diminished the validity of the study results. Furthermore, they found very few studies that considered AT outcomes for children and caregivers of children with disabilities.

Measuring outcomes that are both clinically relevant and are meaningful to assistive technology users

A good place to start when embarking on assistive technology outcomes research is to examine the issues and recommendations that have been raised in the literature in response to evidence that on average 30% of ATDs are misused or abandoned (46, 58-62). For example, researchers agree that there needs to be a good match between the functions and features of the assistive technology, the AT user’s needs and expectations, and the environments in which the device will be used (27, 41, 46, 59, 61, 63). More specifically, persons with physical disabilities are more likely to use devices that enable them to do what they want and need to do, are relatively easy and safe to use, and are durable and reliable. These ideas are consistent with a client and family-centred perspective and with the approach proposed with the PEO model.

Not surprisingly, users express satisfaction with and continue to use devices that improve their function and level of independence. Researchers also agree that the personal meaning that users ascribe to AT usage is very important (27, 41, 60). Personal meaning is influenced by an individual's level of acceptance of their disability, perceptions of competency when using the device, and motivation to do more things independently (with the help of the ATD) rather than relying upon others (60).

While there is demand for better ATD outcomes research, authors agree that, until recently, there were very few appropriate outcome measures available (41, 50, 56, 57, 64). This was particularly true when the studies for this thesis were initiated. At that time there were very few studies that had evaluated the impact of assistive technology on activity and occupational performance of persons with physical disabilities. Nothing of significance had been done in this area to evaluate adaptive seating technologies for children (65, 66), nor to evaluate electronic aids to daily living (EADL) for adults with severe physical disability. This was surprising, considering that many assistive technologies were designed to enhance functional abilities and activity performance. However, it was challenging to find measures suitable for examining these and other relevant outcomes.

Conceptual framework and aims of thesis

The PEO model, together with the ICF, and a client and family-centred philosophy provided a conceptual framework for the studies included in this thesis. The primary goal was to evaluate the impact of specific ATDs (i.e., adaptive seating for children, and EADLs for adults) on activity performance outcomes. Secondary goals were to examine the influence of activity performance on quality of life of ATD users and caregiver assistance. This thesis is organized in two sections based on two distinct clinical populations, types of ATD interventions, and ATD outcomes.

In Section One, the ATD interventions were novel adaptive seating products developed by the research and development team at Bloorview Kids Rehab in Toronto. These products were designed to provide seated postural support for children with neurodevelopmental disorders, such as cerebral palsy. The aim was to give children a stable sitting posture from which they could gain greater volitional control of their upper extremities to engage more fully in play and self-care activities. We wanted to evaluate the impact of these adaptive seating products on activity performance. In addition, we wanted to test our assumption that the amount of caregiver assistance a child needed would change if the child were to gain greater functional abilities. Thus, our secondary goal was to evaluate the impact of the seating interventions on caregiver assistance. Figure 2 shows how the studies in Section One are conceptualized using the PEO model.

Figure 2: Framing the evaluation of adaptive seating devices for children with physical disabilities using the Person-Environment-Occupation Model

Person	Child who is not able to sit without support and consequently has difficulty doing various play and self-care activities
Environment	Adaptive seating devices designed to provide child with supported sitting and stable postural control; expected to free hands for play and self-care activities
Occupation	Specific activities that child or parent wants child to do
Primary outcome	How well child can perform those specific activities; level of satisfaction with child's performance
Secondary outcome	Level of caregiver assistance needed by child to do specific activities

In Section Two, the ATD interventions were electronic aids to daily living (EADL). These technologies are designed to enable persons with severe motor impairments, e.g., spinal cord injury tetraplegia to use electronic devices, such as telephones and personal entertainment systems, for various daily activities (e.g., social calls to friends, arranging appointments, and watching TV). We studied the impact of EADL on activity performance and quality of life. Figure 3 shows how the studies in Section Two are conceptualized using the PEO model.

Figure 3: Framing the evaluation of electronic aids to daily living for persons with severe physical disabilities using the Person-Environment-Occupation Model

Person	Person has severe motor impairments and is completely dependent
Environment	Electronic aids to daily living – designed to give access to electronic devices within the home or workplace
Occupation	Specific activities that can be done by using electronic devices (e.g., watching TV, making phone calls)
Primary outcome	Ease with which a person can perform those specific activities; level of satisfaction with performance
Secondary outcome	Quality of life

Purpose for Thesis

The objective of this thesis is to evaluate the impact of specific assistive technology devices on activity performance, quality of life, and caregiver assistance to advance knowledge about: a) the impact of assistive technology on outcomes that are both clinically relevant and are meaningful to persons with disabilities; and b) the usefulness of specific outcome measures for assistive technology research and clinical practice.

Outline of this thesis

This thesis presents a compilation of published articles from studies that evaluated assistive technology interventions for children and adults with physical disabilities. The first chapter introduces the need for, and the challenges involved in studying the outcomes of assistive technology interventions. It also presents the conceptual underpinnings.

The chapters are organized into two sections. Section one focuses on the impact of seating technologies for children with cerebral palsy on activity performance and level of caregiver assistance. The focus of section two is the evaluation of the impact of electronic aids to daily living on activity performance and quality of life of adults with tetraplegia.

The Canadian Occupational Performance Measure (COPM) was used in Chapters 2 and 4 to evaluate the impact of adaptive seating interventions on the self-care and play performance of children with cerebral palsy. In Chapter 3, the impact of seating interventions on caregiver assistance for selected self-care and play activities was examined.

Two new outcome measures for assistive technology were used in chapter 5 to study the impact of electronic aids to daily living (EADL) on functional performance and quality of life. However, there were limitations with these measures. Thus, in Chapter 6 we established preliminary content validity, discriminant validity, and test-retest reliability for a new device-specific functional outcome measure for EADL. In Chapter 7 we used a generic measure of subjective quality of life to compare the perceptions of EADL users with those of a group of non-users.

In Chapter 8 a summary and general discussion focuses on the study findings and conclusions related to the stated objective of this thesis. Implications for clinical practice and future research are presented.

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1

Section

STUDIES TO EXAMINE THE IMPACT OF ADAPTIVE SEATING ON ACTIVITY PERFORMANCE AND CAREGIVER ASSISTANCE

2

Chapter

Functional impact of a rigid pelvic stabilizer on children with cerebral palsy who use wheelchairs: Users' perceptions

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Abstract

A within-subject ABA design was used to assess the functional impact of a novel wheelchair mounted rigid pelvic stabilizer (RPS) compared with a traditional wheelchair lap belt in a group of six children with cerebral palsy (mean age 10.4 years). The lap belt was replaced with the RPS device. Using the Canadian Occupational Performance Measure (COPM) each subject's self-evaluated performance ability and satisfaction with performance for five key activities was measured at the end of each study phase. Results of repeated measures ANOVAs were statistically significant, indicating that the RPS as compared to the lap belt is a more effective device. The RPS allowed both statistically and clinically significant improvements in occupational performance and satisfaction with performance as measured by the COPM. Visual inspection of subject data confirmed that the performance ratings were higher for the various activities during the treatment phase, compared with the baseline phases. However, in the second baseline phase the performance did not return to initial baseline levels. This suggests that RPS has a facilitating effect for increasing physical functioning. These results are further discussed in terms of implications for practice, and future research.

Keywords

Pelvic stabilization, seating, cerebral palsy, functional outcomes, occupational performance

Introduction

Clinicians, researchers, and industry have recently devoted a considerable amount of attention to the design of wheelchair-based seating systems and their component parts for optimizing pelvic stabilization in individuals with physical disabilities. Most practitioners uphold the assumption that a stable pelvis is fundamental for achieving good postural control and improved functional performance [1-4]. An unstable pelvis invariably limits the comfort and security of wheelchair users. Moreover, pelvic instability reduces the ability of individuals to use their upper extremities because of restricted ability to weight shift according to activities demands, therefore reducing their function and independence within their environments.

For children with cerebral palsy who are non-ambulatory, a major goal is to provide sitting stability through specialized seating devices. However, the most effective technique for enhancing seated pelvic stabilization remains more a matter of clinical opinion than the result of research. An anterior approach to providing stabilization is typically used. A lap belt is the most common form of pelvic stabilization. However, families and clinicians continue to express misgivings about the ease of use and effectiveness of lap belts [5-7]. A critical analysis of the limited number of investigations that examined the effectiveness of pelvic stabilization strategies for children with disabilities, indicated that: (a) the majority of reports are based on anecdotal accounts, therefore lacking empirical data; (b) the scope of outcomes examined are limited to physical variables, such as EMG activity, number of pathological movements, and qualitative aspects of sitting posture, e.g. balance; (c) the outcomes measured are researcher generated; and (d) evidence regarding the efficacy and effectiveness of current pelvic stabilization devices used with children with cerebral palsy remains inconclusive [3].

In the field of assistive technology research, there is growing interest in evaluating client-centered functional based outcomes of assistive devices [8-11]. However, the ability to measure the true impact of any assistive device from a client perspective is a very complex and challenging exercise. Questions, such as the two posed by Ferguson-Pell [12], where he asks ‘whose values?’ and ‘whose outcomes?’, are very important for rehabilitation researchers to generate further discussion concerning the evaluation of specific assistive technology interventions. With respect to seating and mobility intervention research, no studies to date have been conducted that examine impact from a consumer’s perspective.

This study was designed to address this need. The primary research question was: ‘Does a novel rigid anterior pelvic stabilization device for paediatric wheelchair users lead to differences in client-determined occupational performance outcomes?’

The concept of occupational performance used in this study is based on the definition provided by the Canadian Association of Occupational Therapists (CAOT) [13, 14] which emphasizes a client-centred approach, whereby occupational performance is defined by each individual, based on his or her experiences rather than on objective observations.

Occupational performance is defined by the individual in terms of his or her ability to perform certain occupations, and by his or her satisfaction with performance. Occupations are classified as self-care, leisure, or productivity. Self-care includes personal care, functional mobility, and community management. Leisure includes quiet recreation, active recreation, and socialization. Productivity includes paid or unpaid work, household management, school, work, and play.

Methods

Design

A within-subject A1-B-A2 design was used. Single subject evaluation designs are used frequently in applied research in rehabilitation because the primary purpose of these methods is to evaluate treatment effectiveness and document clinically significant improvements in client performance [15]. This design allows for variability across subjects since each subject acts as his or her own control [15, 16]. The 'A1' in the design represents the baseline or the no-treatment phase where a standard pattern of performance was determined. The standard single-anchor-point wheelchair lap belt was the baseline condition used. This phase was 3 weeks in duration. A change of condition was implemented during the 'B' or treatment phase, with the introduction of the rigid pelvic stabilizer. This phase was 5 weeks in duration. The 'A2' phase (withdrawal of intervention) was added to provide greater confidence in the ability to determine the effect of the rigid pelvic stabilizer [15].

Sample

The sample comprised six children with a primary diagnosis of cerebral palsy (mean age of 10.39 years; SD = 0.56; range from 8.3 years to 12.75 years) and his or her primary caregiver. Five children had a diagnosis of spastic quadriplegia, and one was spastic diplegic. There were 4 females and 2 males. All had normal skin sensation and one child had a fixed spinal scoliosis. All were recruited from the Children's Centre of Essex County in Windsor, Ontario. Criteria for inclusion: the ability to sit on a bench using one or both hands for support; currently using a prescribed wheelchair seating system that had a pre-ischeal shelf and posterior superior iliac spine (PSIS) support. Table 1 presents the relevant subject characteristics. All but two children had prior experience with using the Metalcraft † Sub-ASIS pelvic stabilizer. The primary caregiver was each child's mother, except for one case where the school aide participated. All participants provided informed consent before becoming involved in the study.

Table 1 Subject's characteristics

Grade level	Special Education Support	Current Rehabilitation	Wheelchair (WC) type	WC function	WC use Daily (hours)
6	Part-time educational assistant	OT, PT, SLP	Power	Independent all the time	9
3	Full-time educational assistant	OT, PT	Power	Independent	8
7	Integrated Classroom	OT, PT	Power	Independent	12
N/A	Full-time educational assistant	OT, PT, SLP	Power	Independent	12
N/A	Segregated Classroom	OT, PT	Manual	Independent for short distances only	7.5
3/4	Segregated Classroom	OT, PT, SLP	Power	Independent	11

Rigid Pelvic Stabilizer

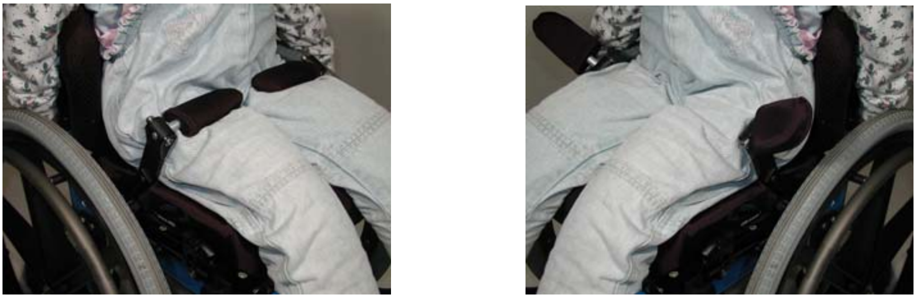
The purpose of the rigid pelvic stabilizer (RPS) is to improve seated postural stability in children with spasticity. The design of the RPS used one pair of laterally-placed support assemblies to replace the function of the lap belt. The assemblies were independently adjusted to hold the child below the anterior superior iliac spine (ASIS) and resisted anterior and upward movement (figures 1a and 1b). Each RPS assembly consisted of three major parts: a support pad, a release mechanism and seat bracket. The support pad was the only part of the RPS assembly that contacted the child. In order for the RPS to effectively control unwanted movements of the pelvis, it is necessary that it be used in a seating system fitted with a pre-ischeal shelf and a posterior superior iliac spine (PSIS) support.

In its tested configuration, the pad was a 100 mm x 19 mm elliptically-shaped epoxy form with a foam-cushioned perimeter. It was supported along its long axis by a 12 mm diameter aluminium rod. This arrangement permitted the pad to be positioned and fixed laterally below the ASIS. As a unit, the pad and rod freely rotated within the release mechanism housing. The rotational movement allowed the flat, broad surface of the pad to self-orient along the anterior surface of the child's thigh. A removable nylon sleeve was supplied as a cosmetic cover for the pad.

The release mechanism connected the support pad and rod to the seat bracket. It consisted of a low-friction, plastic housing and spring-loaded plunger mechanism. By depressing the plunger mechanism, the housing could be rotated to lock the position of the support pad and rod assembly either horizontally or vertically (see figures 1a and 1b). The former position was the 'in-use' position, while the latter position allowed the child transfer into or out of the seat.

The seat bracket was a 45 mm x 3 mm steel flat that connected the release mechanism to the inferior surface of the seat. The bracket was formed with a 90° bend to hold the RPS system along the lateral edge of the seat. The long leg of the bracket extended upwardly and forwardly at 60° to the horizontal. It had an overlapping 32mm x 3 mm steel section that provided length adjustment in 9.5 mm increments. This provided precise vertical placement of the RPS support pad during the fittings. The short leg of the bracket connected RPS system to the seat through a screw and threaded insert arrangement. This bracket section was slotted to allow 30 mm horizontal adjustment of the RPS assembly along the seat's length.

Figures 1a and 1b Rigid pelvic stabilizer on child's wheelchair: in closed and open position



Measurement

The Canadian Occupational Performance Measure (COPM) was used to evaluate functional impact [17]. The COPM was designed as an outcome measure with a semi-structured interview format and structured scoring method to: (1) identify and prioritize problem areas in occupational performance among clients with a variety of disabilities and across developmental levels; (2) evaluate self-perception of performance and satisfaction relative to problem areas; and (3) measure changes in client's perception of his/her occupational performance over time. Results of a number of validation studies show that the COPM demonstrates good test-retest reliability [20, 21] and content validity [17, 22, 23]. Evidence of criterion and construct validity [24, 25] and responsiveness of the COPM is also provided [26, 27]. Complete guidelines for the administration and scoring of the COPM are contained in the COPM manual [17]. The COPM uses three 10-point rating scales to rate importance, performance, and satisfaction. A score value of '1' refers to a low rating, i.e.

'not important at all', 'not able to do at all', 'not satisfied at all'. A score value of '10' refers to a high rating, i.e. 'extremely important', 'able to do it extremely well', 'extremely satisfied'.

Procedures

A trained paediatric occupational therapist with more than 20 years of experience working with children with cerebral palsy who require adaptive seating was hired as the research therapist to administer the COPM. The COPM was administered at four different occasions. It was first during the context of an initial interview (pre-baseline) to identify and prioritize the five main occupational performance issues for the child and his/her caregiver. It was administered again following the baseline (A1), treatment (B), and second baseline (A2) phases. The COPM was administered according to the procedures in the manual [17].

Since the caregiver was responsible for ensuring that the child wore the lap belt or the RPS over the course of the study, the COPM was administered to each child with his or her caregiver present. Participant dyads (child and caregiver) were instructed to consider the needs, expectations, and views of the child while providing responses. Specifically, a typical day for the child was discussed, and each child was asked to identify at least five bimanual activities that he or she wanted to do, needed to do, or was expected to do while in his or her wheelchair. The dyads were guided to break down activities in order to focus on the aspects of the activity that were difficult for the child. For example many children identified difficulty with eating lunch. An activity-analysis approach assisted in identifying the specific aspects that were difficult for the child, such as opening plastic containers, using spoon or fork, and using knife and fork to cut food. Once activities were identified, participants rated how important each activity was to them using the 10-point importance rating scale. Participants also completed a self-evaluation of their current performance. These self-evaluations of performance and satisfaction were completed following the (A1), (B) and (A2) phases.

Data Analysis

It has been argued that in single-subject designs the use of both visual inspection and statistical analysis methods provide complementary information related to treatment impact and thereby enhance confidence in the conclusions based on the data [15, 28]. To this end, the COPM scores were graphically analysed and visually inspected for clinically significant changes. Repeated measures ANOVA procedures were used to examine, on a group level, if significant differences existed in COPM performance and satisfaction scores between study phases. The computer program SPSS windows™ version 9 was used for these analyses.

Results

COPM Importance Ratings

The important occupational performance activities that were identified by each subject using the COPM are listed in table 2. The occupational performance classification scheme in the COPM was used to sort the activities across subjects. It showed that 73% (22/30) were self-care activities, while 27% (8/30) were productivity activities. There were no leisure activities identified. Overall, a high level of importance was associated with the majority of the activities, with 80% (24/30) of the activities rated a '6' or higher on the 10-point importance rating scale (table 2).

COPM Performance and Satisfaction Ratings

Mean COPM performance and satisfaction scores were calculated for each subject by summing the ratings across the five activities and dividing by the total number of activities (as outlined in the COPM manual). These results are presented for each subject for the three phases of the study in figures 2a and 2b. Mean performance change scores from A1 baseline to treatment ranged from 2 - 4.6 across subjects (figure 2a), and from 2.8 - 5.8 across subjects for satisfaction scores (figure 2b). To determine if these changes were statistically significant, repeated measures ANOVAs were conducted. The results of tests of sphericity were non-significant, confirming that the analysis model was appropriate. The results of these analyses showed statistically significant changes between baseline and treatment phases. For COPM performance scores, from A1 baseline to treatment, $F = 68.21$, $p = 0.0001$, and from treatment to A2 baseline, $F = 32.41$, $p = 0.002$. For COPM satisfaction scores, from A1 baseline to treatment, $F = 81.48$, $p = 0.0001$, and from treatment to A2 baseline, $F = 21.86$, $p = 0.005$.

Individual subjects' scores were also graphed to describe, at the activity level, the changes that occurred as a result of the RPS device (figures 3a and 3b to figures 8a and 8b). Four subjects (#3, #4, #5, #6) rated their performance and satisfaction with performance higher for all activities during the treatment phase as compared to both baseline phases (figures 5-8). The other two subjects (#1 and #2) rated their performance higher for four out of five activities during the treatment phase, as compared to the baseline phases (figures 3a and 4a). However, with respect to satisfaction with performance, subject #1 rated her satisfaction with performance on all activities (including the one task where performance had not changed) higher during the treatment phase as compared to baseline (figure 3b). Subject #2 reported no change in satisfaction with performance for the same task where performance had not changed (figure 4b).

Table 2: Activities identified on COPM and importance ratings

Subject	Activities identified by each child on COPM	Imp.
1	(1) Computer typing on an adapted keyboard (2) Eating using a fork, specifically getting the food onto the fork. (3) Drinking with less spillage from a cup with no handles and no lid. (4) Wheelchair driving with a more upright posture in chair. (5) Brushing hair, specifically brushing any part of the head	9 9 7 10 4
2	(1) Printing - better stabilization of paper and symmetry of letter formation. (2) Cutting using standard pair of long blade scissors and left hand to assist. (3) Putting on pullover jacket using flip over method. (4) Opening plastic containers using left hand to stabilize container. (5) Buttering bread using left hand to stabilize bread and spreading butter evenly over bread with right hand.	10 7 8 8 5
3	(1) Typing on a computer using both hands to access keys. (2) Writing, specifically improved penmanship. (3) Cutting food, specifically meat using knife and fork (4) Putting toothpaste on toothbrush. (5) Opening plastic containers of various sizes.	10 8 10 6 9
4	(1) Computer typing with increased speed and less fatigue. (2) Writing name using a standard ball-point pen (3) Eating using a spoon or fork with less spillage. (4) Putting shirt on, specifically getting arms into the sleeves. (5) Drinking from a cup with no handles and no lid, with less spillage.	10 10 10 5 10
5	(1) Opening plastic lunch containers of two different sizes. (2) Putting toothpaste on toothbrush holding tube in right hand and the brush in the left. (3) Wheelchair driving using two hands with increased speed and more direction accuracy. (4) Brushing hair on whole head. (5) Putting on coat using flip over head method.	4 9 9 5 7
6	(1) Brushing teeth on right side of mouth on the top and bottom. (2) Brushing hair at back of head. (3) Computer typing using both hands (4) Turning pages of a book with stiff pages using right hand to stabilize the book. (5) Transferring nonbreakable dishes from the wheelchair to the kitchen counter and or sink.	9 9 8 6 5

Legend: Imp. = importance

Figure 2a: COPM performance ratings for each participant in each study phase

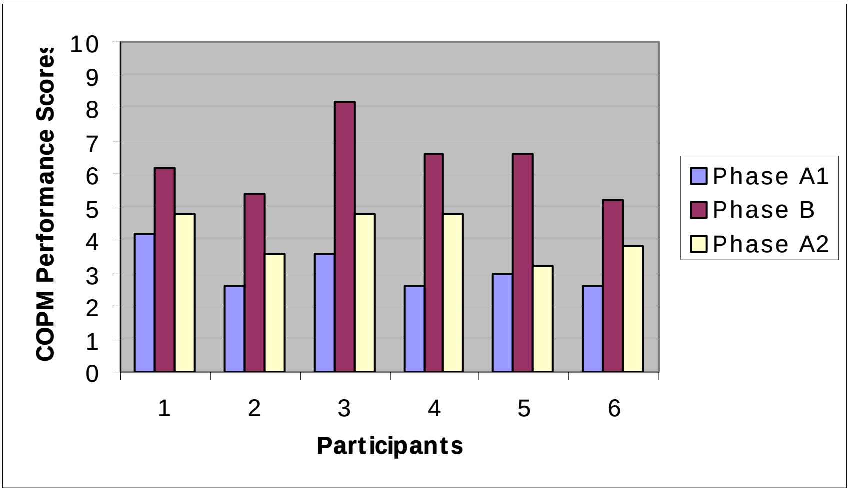


Figure 2b: COPM satisfaction ratings for each participant in each study phase

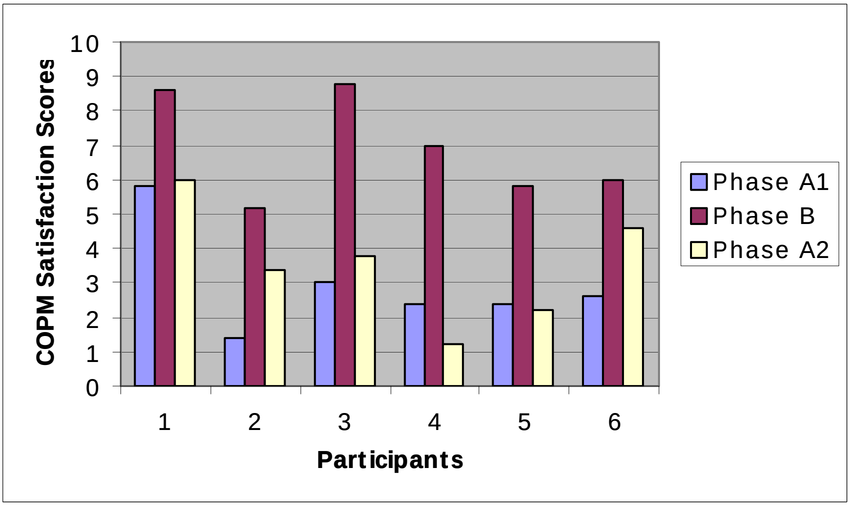


Figure 3a. Subject #1: COPM Performance Scores for 5 Tasks

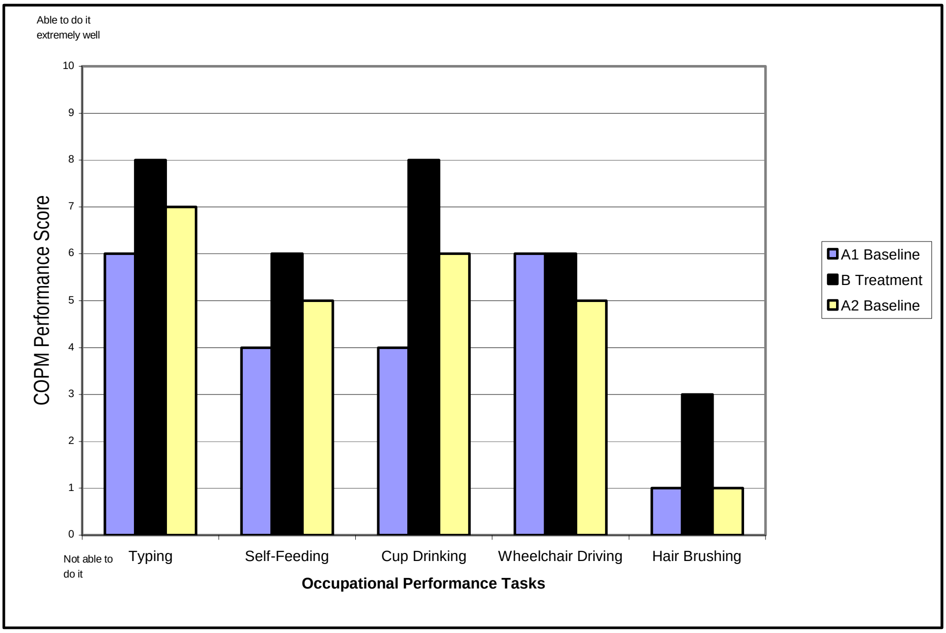


Figure 3b. Subject #1: COPM Satisfaction Scores for 5 Tasks

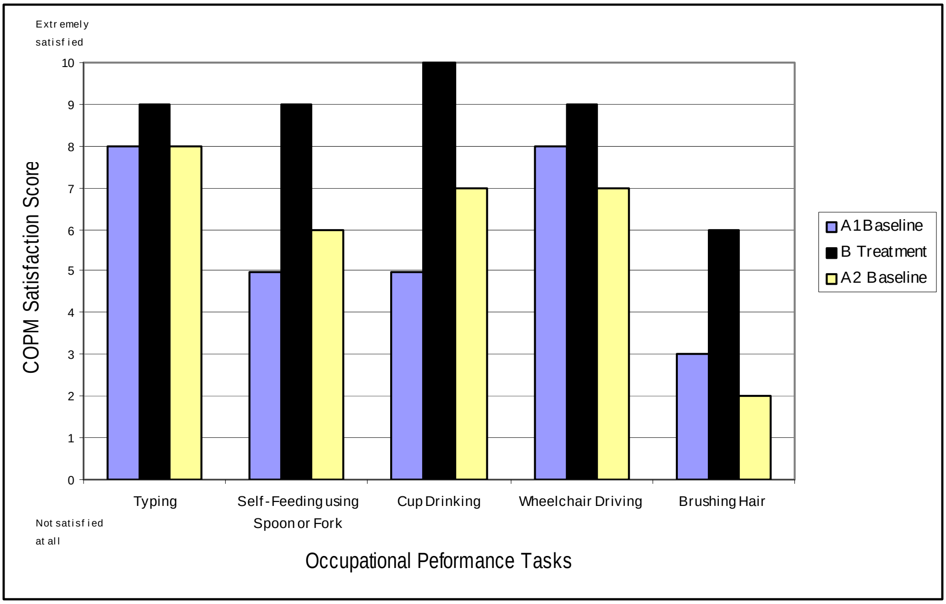


Figure 4a. Subject #2: COPM Performance Scores for 5 Tasks

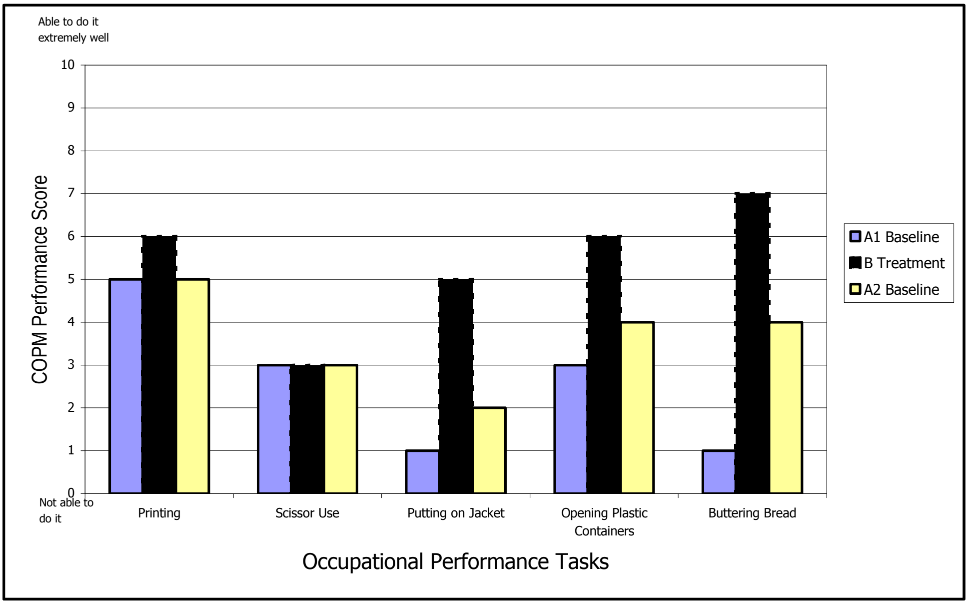


Figure 4b. Subject #2: COPM Satisfaction Scores for 5 Tasks

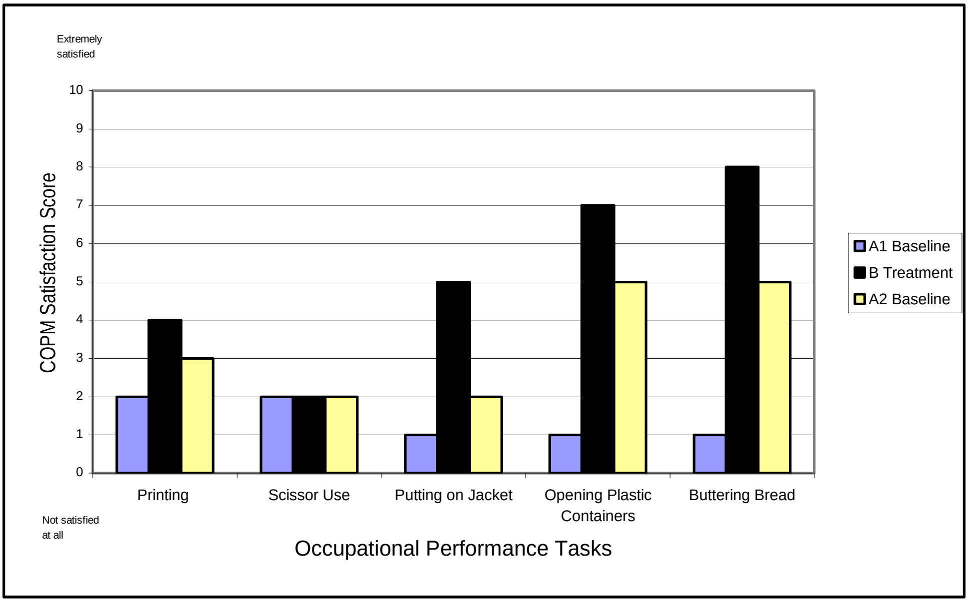


Figure 5a. Subject #3: COPM Performance Scores for 5 Tasks

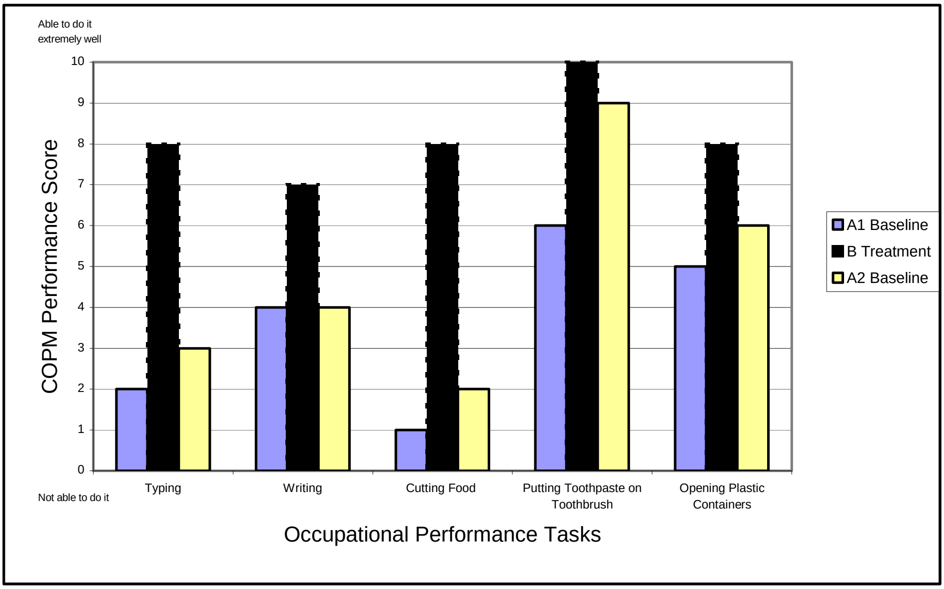


Figure 5b. Subject #3: COPM Satisfaction Scores for 5 Tasks

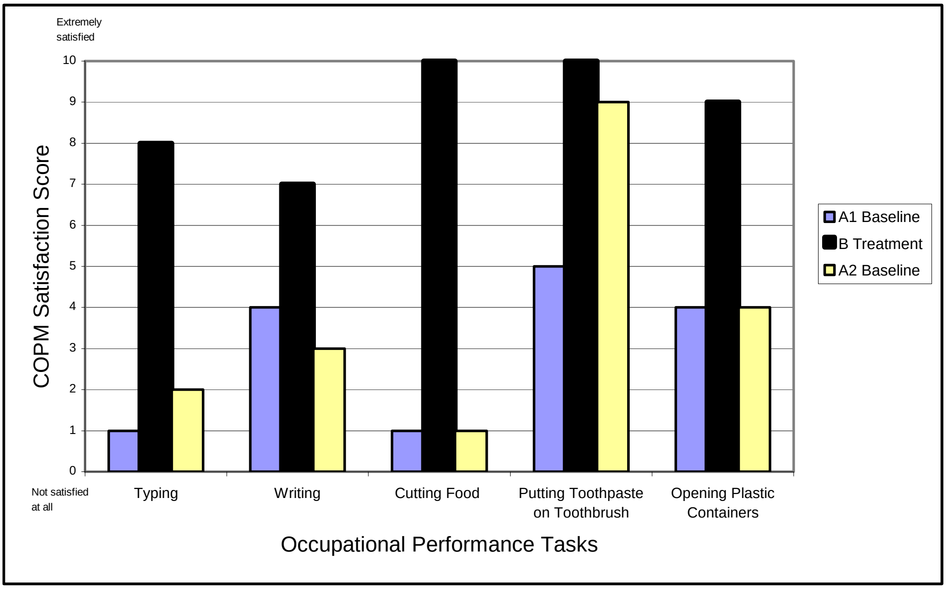


Figure 6a. Subject #4: COPM Performance Scores for 5 Tasks

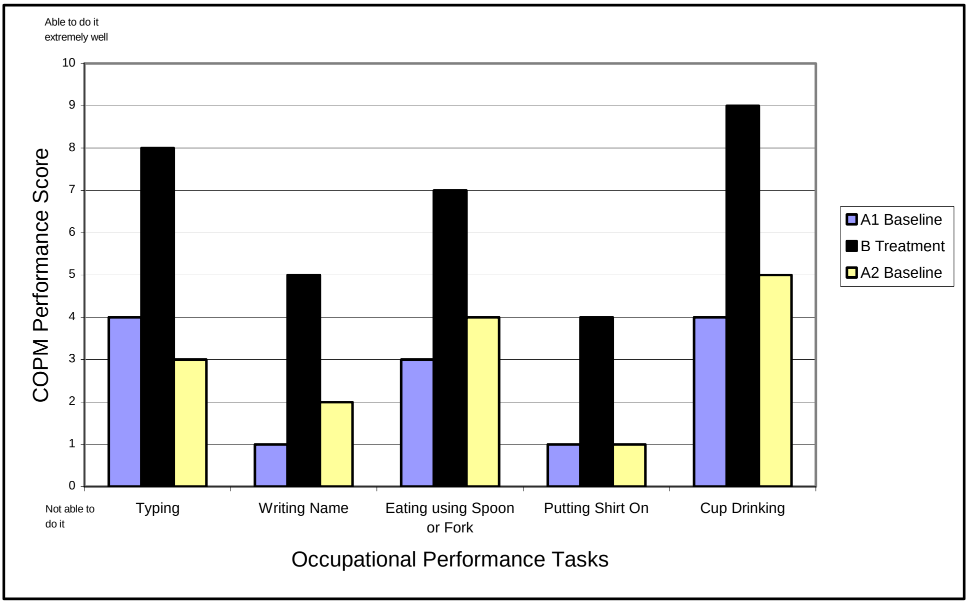


Figure 6b. Subject #4: COPM Satisfaction Scores for 5 Tasks

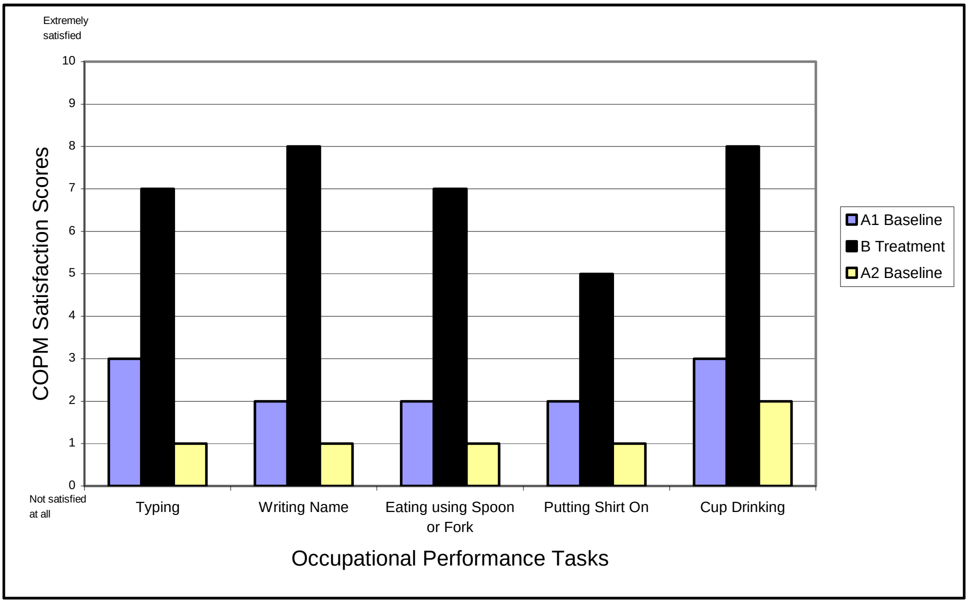


Figure 7a. Subject #5: COPM Performance Scores for 5 Tasks

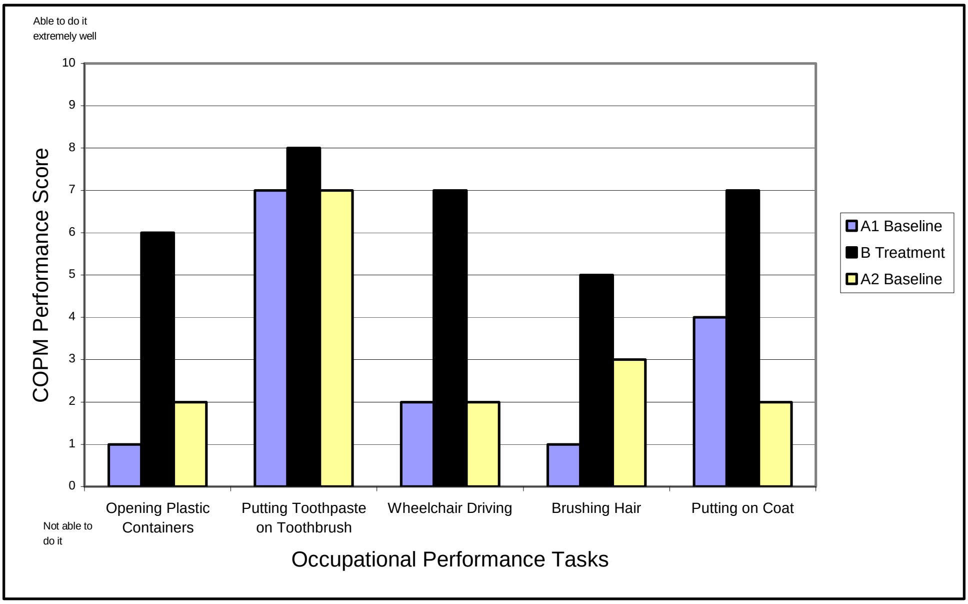


Figure 7b. Subject #5: COPM Satisfaction Scores for 5 Tasks

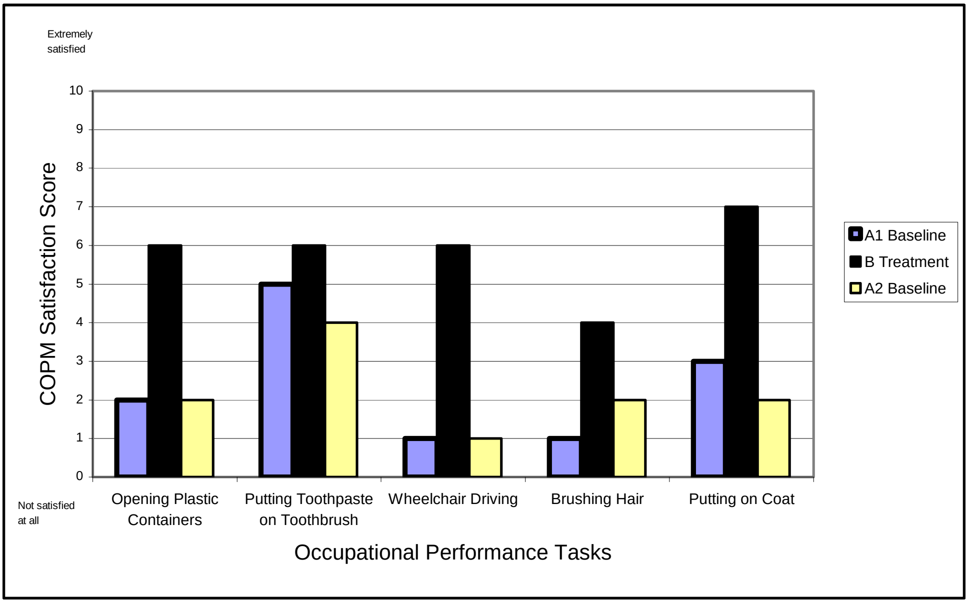


Figure 8a. Subject #6: COPM Performance Scores for 5 Tasks

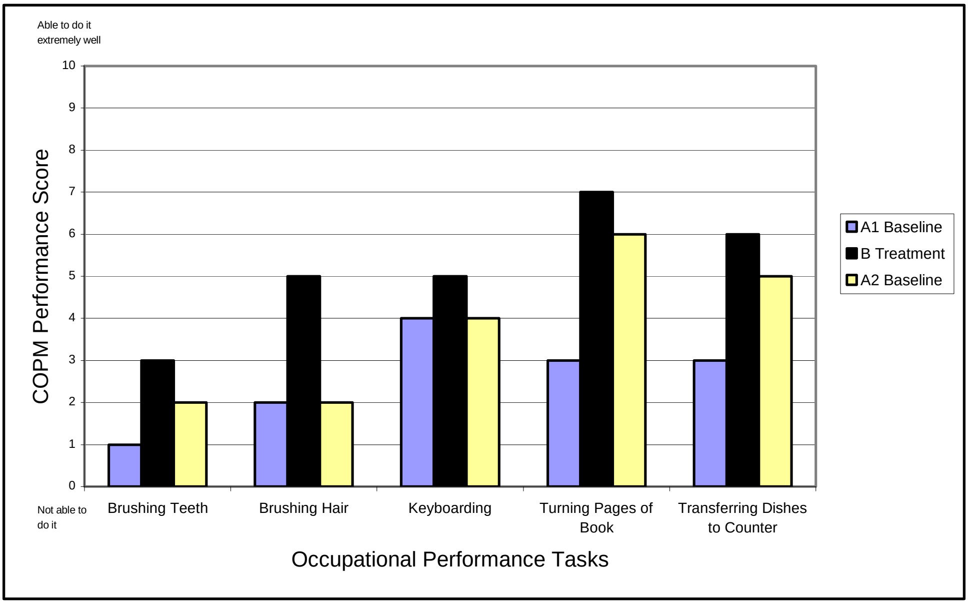
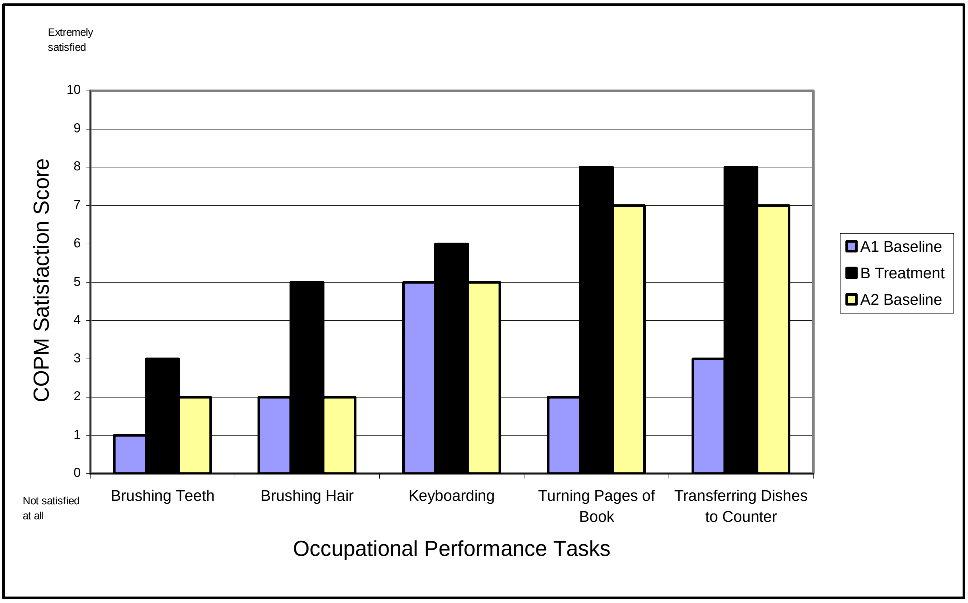


Figure 8b. Subject #6: COPM Satisfaction Scores for 5 Tasks



Each subject's performance scores were also compared between the two baseline phases to examine potential carry-over effects of the treatment. Subjects generally rated their performance for most activities (3/5) higher during the A2 phase as compared to the A1 phase, while no change was noted for the other activities (figures 3a-8a). With respect to how subjects rated their satisfaction with performance during the two baseline periods, the trend was different (see figures 3b-8b). With the exception of subject #2, subjects were more dissatisfied with their performance for most activities or their level of satisfaction did not change at the A2 phase as compared to the A1 phase.

Discussion

This study showed that the RPS has the potential to change the occupational performance as perceived by children with cerebral palsy. Data analysis revealed statistically significant improvements in performance and satisfaction with performance for self-identified functional activities as measured with the COPM [17]. The clinical relevance of this finding was confirmed when data from each subject were visually analysed. Prior research indicates that change scores of two or more points on the COPM are clinically important [17]. In this study, change scores ranged from 2 to 5.8 across subjects (figures 2a and 2b).

It is not surprising that the distribution of activities that were identified by the subjects in this study were primarily self-care (73%) and productivity (27%), or school related activities (table 2). Given the age of the subjects, they spent the majority of their day at school, therefore morning routine activities such as brushing teeth, lunch time activities such as opening plastic containers, and classroom activities such as computer typing were important ones. Results of pilot testing using the COPM found a similar distribution of occupational performance problems, where most activities were classified as self-care and fewer as leisure [24].

As seen in this study and others [2], children with cerebral palsy differ in many characteristics resulting from the diffuse nature and timing of the neurological impairment that occurs [29]. For this reason, the use of a single-subject repeated measures research design allowed subjects' scores to be compared against their own reassessment scores, therefore controlling for their unique differences.

Individual subject data analysis was important because it provided important information regarding the magnitude and direction of changes over time. For example, each subjects' task performance and satisfaction with their performance was better when the RPS was worn, as compared to using the lap belt, with the exception of only two subjects (#1, #2) where performance did not change for one of their five tasks.

The functional gains observed for a 3-week period for some children after the device was removed suggest that the RPS may facilitate the development of the seated postural control mechanism essential for performing upper-extremity functional skills [2]. Another reason why, for some children, performance did not return to initial baseline levels on some activities is related to the process used with the COPM. By self-identifying specific activities, children were aware of their performance changes and were satisfied with their achievements, therefore their perceptions could have been modified over time. Further research is required to examine these two explanations.

The main outcome measure used in this study was the COPM [17]. This tool was not designed to assess a client's function through direct observation. Instead, the COPM was designed to assess a person's self-perceived performance and his or her satisfaction with their performance. Client-identified functional goals and satisfaction with outcome are important aspects of evaluation of the effectiveness of rehabilitation [30]. Further research using a valid and reliable observational functional rating scale would, however, add to the accumulated knowledge regarding this intervention. Replicating this study with different clients would also strengthen the internal validity of these results.

In summary, this study has shown that the RPS is an effective device for improving the functional performance of children with cerebral palsy who are wheelchair users. The results of this study support the basic assumption that a key determinant of increased functional ability is enhanced seated postural stability achieved through pelvic stabilization [1-4].

Plans for incorporating the RPS into a new modular adaptive seating system for children are under way through the Ontario Rehabilitation Technology Consortium. Plans for further clinical field trials and commercializing the RPS are in place.

Acknowledgements

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3
Chapter

Effects of a wheelchair-mounted rigid pelvic stabilizer on caregiver assistance for children with cerebral palsy

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Abstract

A within subjects repeated measures (A1,B,A2) design was used to study the impact of a rigid pelvic stabilizer (RPS) compared with a traditional lap belt on the caregiver assistance requirements of six children with cerebral palsy while they completed functional tasks from their wheelchair seating system. A lap belt was worn during the 3-week baseline phases (A1 & A2). The RPS was used during the 5-week intervention phase (B). At baseline each child and parent identified 5 bimanual or reaching tasks with which the child had difficulty. Each parent rated the degree of assistance the child required to do each task using a 6-point scale. Parents also maintained a log to record how many times the child was repositioned daily. The RPS appeared to impact directly on reducing caregiver assistance for 30% of the tasks, as the need for assistance was less during Phase B, when the RPS was used, and was greater during Phases A1 and A2, when the lap belt was worn. Repositioning of five children was needed less often during phase B than during the A phases. The RPS reduced the child's need for caregiver assistance for some bimanual and reaching tasks and for repositioning the child.

Key Words

Adaptive seating, single subject research design, caregiver assistance, functional outcomes, occupational performance, children with cerebral palsy

Introduction

Many rehabilitation professionals believe that a stabilized pelvis is fundamental to seated postural stability for a child with adaptive seating needs, and that this in turn enhances performance of day to day tasks (1, 2). When sitting is not stable, the child with cerebral palsy assumes spastic postures that restrict volitional hand and arm function (3). Stabilizing the child at the pelvis, through adaptive seating interventions, can reduce pathological influences of tone on movement and enable the child with spastic cerebral palsy to use more controlled volitional movement for function (4, 5).

The functional improvements that result from greater pelvic stability, achieved through a seating intervention, may reduce the child's need for assistance in completing daily tasks. Several studies describe the connection between physical dependency of children with physical disabilities and caregiver stress (6-9). Although these studies used small sample sizes, and did not explore the demands associated with caring for a child with a physical disability in a comprehensive manner, they suggest that there are many benefits associated with improving a child's functional independence and reducing a child's dependency on caregivers for assistance. Wright and Bortolussi (9) found that parents of children with cerebral palsy who reported a lower burden of care provided less caregiver assistance than parents who reported a higher burden of care. The burden reported was of both a physical and psychological nature.

Clinicians whom prescribe adaptive seating systems for children with spastic cerebral palsy are challenged to choose device options that enable the child to maintain a stable seated posture. A new rigid pelvic stabilizer (RPS) was designed to improve the seated postural stability of children with spasticity. The RPS is an alternative to the traditional lap belt for children's wheelchair seating systems. We conducted a study to evaluate the effectiveness of the RPS in stabilizing the posture of children with cerebral palsy, freeing the arms for reaching and the hands for bimanual functions such as manipulating toys for play or managing paper and pencil tasks at school. In addition, we proposed to measure the impact of the RPS on the amount of caregiver assistance the child required during day to day task completion.

The central purpose for this study was to evaluate task performance (i.e., using both hands to perform daily tasks such as propelling a wheelchair or putting toothpaste on a toothbrush), and caregiver assistance for children using a rigid pelvic stabilizer system compared with a lap belt on their adaptive wheelchair seating system. The results pertaining to the evaluation of task performance are reported elsewhere (4). We found that each child and his or her caregiver rated significant improvements in his or her performance of specific daily tasks when the RPS rather than a lap belt was used. The child participants and their caregivers also reported greater satisfaction with the performance of the identified tasks when the RPS was used. These findings upheld the clinical assumption that pelvic stability is the foundation for functional skill development. In this paper, we analyze our data to test the assumption that a seating intervention used to increase pelvic stability can help to reduce the child's dependency on assistance from caregivers for performing daily tasks.

Methods

Design

A within subjects, repeated measures (A1, B, A2) design was used to evaluate a specific seating intervention, the RPS, and to allow for variability across the children included in this study. The A phases (A1 and A2) were baseline phases, and the RPS intervention was used during phase B. Each participating child used a seating system lap belt, anchored at 2 points, for the first 3 weeks (phase A1) and the final 3 weeks of the study (phase A2), and used the RPS for the middle 5 weeks (phase B). The same measurement procedures were maintained throughout the three phases (Figure 1).

Figure 1: ABA Study Design

Phase A1 (3 weeks)	**Phase B (5 weeks)**	**Phase A2 (3 weeks)**
Lap Belt	Rigid Pelvic Stabilizer (RPS)	Lap Belt
COPM at start and end of Phase A1	COPM at end of Phase B	COPM at end of Phase A2
Occupational Performance Interview conducted weekly using CGA		
Daily log maintained by caregiver		
Daily log maintained by child		

Legend:
COPM = Canadian Occupational Performance Measure (Law et al., 1994)
CGA = Adapted Caregiver Assistance Scale (Haley et al., 1992)

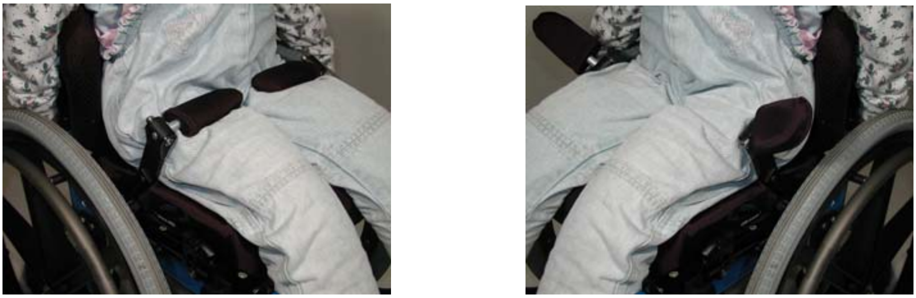
Sample

Six children, 4 girls and 2 boys, between the ages of 8 to 12 years (mean age of 10 years, 4 months) were recruited from a regional children's rehabilitation centre and assented to participate in this study. Consent was obtained from their primary caregivers. Five children had a diagnosis of cerebral palsy, spastic quadriplegia and one had a diagnosis of spastic diplegia. Only Child #1, with a fixed skeletal deformity and a rotated pelvis, was unable to achieve neutral hip adduction. All were able to maintain their seated posture using one or both hands for support when sitting unsupported on a bench, and all had a mobile pelvis that could achieve a neutral or anterior tilted position. All children used their own wheelchair seating system that had a pre-ischeal shelf and support at the level of the posterior superior iliac spine (PSIS). Five of the children were using their seating systems for a minimum of 6 months before this study, while one child had had her seating system fitted two months before she participated in the study. At the start of the study, five children were independently mobile using their power wheelchairs, while the only child that used a manual wheelchair was independent in mobility for short distances. Five of the children's mothers and one child's school aide were the caregiver respondents.

The Rigid Pelvic Stabilizer

Several types of subASIS bars, which provide rigid pelvic stabilization, have been discussed in the literature and are available to seating clinicians (1). The RPS used in this study is a new subASIS stabilizer and was designed through a research and development project with considerable input and guidance from seating system consumers and clinicians familiar with the seating needs of children with spasticity (5). The RPS was under development at the time of this study and was only used during this study. The families were made aware that the device was an advanced prototype and was not available for them to keep after the study. The RPS is a pair of pads that hold the user below the anterior superior iliac spines (ASIS) to minimize unwanted movements of the pelvis (see figures 1a and 1b). The system is designed to improve the seated postural stability of children with spasticity. The RPS uses adjustable pads to accommodate mild to moderate asymmetries at the pelvis that are commonly associated with spastic musculature (1). The RPS was designed to be used on a seating system fitted with a pre-ischeal shelf and PSIS support to effectively control movement of the pelvis.

Figures 1a and 1b Rigid pelvic stabilizer on child's wheelchair: in closed and open position



In the configuration used during this study, the RPS pad was a 100-mm x 19-mm elliptically-shaped epoxy form with a foam-cushioned perimeter. It was supported along its long axis by a 12-mm diameter aluminum rod. This arrangement permitted the pad to be positioned and fixed laterally below the ASIS. As a unit, the pad and rod freely rotated within the release mechanism housing. The rotational movement allowed the flat, broad surface of the pad to adjust the fit along the top of the child's thigh. A removable nylon sleeve was supplied as a cosmetic cover for the pad. The support pad and rod were connected to the seat bracket with a release mechanism, which allows the stabilizer arms to swing up and out of the way to permit the child to transfer. The seat bracket was a flat piece of steel connected to the inferior surface of the seat. The system was adjustable for placement along the length of the seat, and for width and depth of the child's thighs. The RPS was fitted snugly over the top of the thighs and beneath the ASIS for each child at the start of week 4 and removed from the seating system at the end of week 8.

Measurement

The Canadian Occupational Performance Measure (COPM) (10) was used by the child and caregiver(s) to identify 5 important, meaningful problems in occupational performance experienced by each child while using his or her wheelchair at home and/or at school. The amount of caregiver assistance required by the child to engage in each of the occupational performance areas identified on the COPM was also measured. The Caregiver Assistance Scale from the Pediatric Evaluation of Disability Inventory (PEDI) (11), was modified for this purpose (Fig. 2), and was used during a weekly occupational performance interview (OPI) with the child's primary caregiver. When used in the PEDI, the ratings of caregiver assistance are applied to a group of items in the domains of self-care, mobility and social function. For the purposes of this study, we gained permission from the PEDI authors to apply the scale to the specific functional problems identified for each child on the COPM (S. Haley, personal communication, May, 1998). The PEDI has proven to be a valid, reliable functional assessment for children with physical disabilities (12).

During each interview, caregivers were encouraged to comment upon the child's performance of each selected task, to provide a clearer picture of the child's experiences. Caregivers kept a daily log, and used a 4-point scale to rate the number of times the child needed to be repositioned in his or her seating system that day (Fig. 3).

Figure 2: Caregiver Assistance Scale modified from the PEDI (Haley et al., 1992)

6	TOTAL ASSISTANCE	Caregiver does *ALMOST ALL* of activity; child provides no meaningful assistance
5	MAXIMAL ASSISTANCE	Caregiver does *MORE THAN HALF* of the activity; child provides meaningful assistance
4	MODERATE ASSISTANCE	Caregiver does *LESS THAN HALF* of the activity.
3	MINIMAL ASSISTANCE	Caregiver provides *VERY LITTLE* assistance, such as occasional postural stabilization or assistance with the completion of the activity.
2	SUPERVISION / SET UP	Caregiver provides *NO PHYSICAL HELP* during the activity, but is needed to *MONITOR, PROVIDE VERBAL DIRECTIONS, OR SET UP ASSISTIVE DEVICES OR MATERIALS*.
1	INDEPENDENT	Caregiver provides *NO PHYSICAL ASSISTANCE OR SUPERVISION*

Figure 3: Caregiver Daily Log – Repositioning of Child

Please check (✓) the number of times (child's name) was repositioned in his or her seating system today, while using the seating system. This does not include the number of times the child was transferred in and out from the seating system.

1. more than 3 times	2. 2-3 times	3. 1 time	4. 0 times

Procedures

As part of the COPM protocol, the child and caregiver were asked to review what the child does during a typical day and to identify bimanual tasks that the child wants to do, is expected to do, or needs to do while using his or her wheelchair. The child and caregiver were guided to break down occupations, such as brushing teeth, into the smaller component parts, such as the task of putting toothpaste on the toothbrush, to focus on the aspects that were difficult for the child to perform. The child and parent then rated the child's performance and their satisfaction with the child's performance. Reid et al. (4) report the findings from this part of the study.

The OPI was conducted weekly by phone or in-person with each child's caregiver. The interviews were typically made on the same day each week. The caregiver was asked to rate the amount of assistance the child required for each functional problem during that week and to comment on the child’s performance. The caregiver also maintained a daily log to chronicle the number of times the child was repositioned in his or her wheelchair seating system.

Data Analysis

The caregiver assistance data were summarized for each participant into graphs and onto tables, and visually analyzed for trends across the eleven weeks of the study. The caregiver comments were sorted by task and analyzed across the 3 phases of the study, with attention paid to links with the caregiver ratings. The daily ratings made by the caregiver about the number of times the child was repositioned were sorted by week and graphed for visual inspection of data trends.

Results

Caregiver Assistance Ratings and Parent Comments

Caregiver assistance ratings were consistently recorded at baseline and weekly for each task for all children across the 11 weeks of OPI interviews. The only missing rating is for Child #1’s driving accuracy during week 2. Parents included comments during the OPI for 91% of the time during phase A1, 100% of the time during phase B, and 99% of the time during phase A2.

Child #1 identified bimanual typing, self-feeding, drinking from a cup, driving accuracy and brushing hair (whole head) as the five most important tasks that she had difficulty doing from her wheelchair (Table 1). Ratings for caregiver assistance did not change over the duration of the study for typing and driving accuracy. From analysis of comments it was evident that this child could not fully reach the keyboard when using the lap belt, and that reach improved when the RPS was used. The caregiver also described better sitting posture and less need for verbal reminders for driving accuracy when the RPS was used. During phase A1, the child required maximal assistance with feeding and drinking, but only moderate help with these two tasks through the remaining 8 weeks. The caregiver commented that during the A phases the child was messier, spilled more during eating and drinking, and was more fatigued. The caregiver felt the child used the utensils and cup with less effort and with greater stability during phase B. The caregiver assistance for hair brushing was less during phase B than for both A phases, and the caregiver commented that the child’s reaching ability improved throughout phase B.

Table 1: Caregiver Assistance Weekly Ratings for Child 1

Tasks:	**BL**	**Phase A1**			**Phase B**					**Phase A2**		
Typing	4	4	4	4	4	4	4	4	4	4	4	4
Feeding self	5	5	5	5	4	4	4	4	4	4	4	4
Drinking	5	5	5	5	4	4	4	4	3	4	4	4
Propelling w/c	4	4	*	4	4	4	4	4	3	4	4	4
Brushing hair	6	6	6	6	6	6	5	5	5	5	6	6

Table 2: Caregiver Assistance Weekly Ratings for Child 2

Tasks:	**BL**	**Phase A1**			**Phase B**					**Phase A2**		
Writing	3	3	3	3	3	3	3	3	3	3	3	3
Scissor cutting	5	5	5	5	5	5	5	5	5	5	5	5
Putting on coat	6	6	6	6	6	6	6	6	5	5	6	6
Removing lid	4	4	4	4	4	3	3	3	3	4	4	4
Buttering bread	6	6	6	6	5	5	5	5	4	4	5	5

Scale found in Figure 2
BL = Baseline; * = missing data point

Child #2 identified the following tasks as most important: writing while stabilizing paper, cutting with scissors, putting jacket on, removing lids from plastic containers and buttering bread. Caregiver assistance for the tasks of writing, cutting and putting jacket on did change during the 11-week study. Less assistance was needed during phase B, compared with the A phases, for the task of removing lids from plastic containers. Child #2 needed marginally less assistance with buttering bread in phases B and A2, than during phase A1. Her caregiver commented that she had a more stable posture when the RPS was used and this improved her manual motor control. Comments also indicate that she spilled less when manipulating containers and could spread butter over a greater surface of the bread during the weeks when she used the RPS.

Child #3 focused on bimanual keyboarding, writing while stabilizing paper, cutting food, applying toothpaste on his toothbrush and removing lids from plastic containers as shown in Table 3. Keyboarding was accomplished independently throughout the study. However, Child #3's mother pointed out that he had greater endurance and less pain and fatigue for after school activities, such as keyboarding and handwriting, during the weeks when he used the RPS, compared with the weeks he used the lap belt. He required progressively less assistance with writing and toothpaste once he began using the RPS, and his skills did not diminish when he began to use the lap belt again during phase A2. Child #3 required total assistance with cutting food for the first 8 weeks of the study, and minimal assistance for the final 4 weeks. He was independent with removing lids from plastic containers during phase B only, whereas he needed moderate caregiver assistance when he used the lap belt. His caregiver pointed out that he was messier when he managed containers and utensils during the weeks when he used a lap belt. She also noted that his posture was more stable when he used the RPS.

Table 3: Caregiver Assistance Weekly Ratings for Child 3

Tasks:	BL	Phase A1			Phase B					Phase A2		
Keyboarding	1	1	1	1	1	1	1	1	1	1	1	1
Writing	3	3	3	3	2	2	1	1	1	1	1	1
Cutting food	5	6	6	6	6	6	6	6	2	4	4	4
Applying toothpaste	4	4	4	4	2	2	1	1	1	1	1	1
Removing lid	4	4	4	4	1	1	1	1	3	4	4	4

Table 4 : Caregiver Assistance Weekly Ratings for Child 4

Tasks:	BL	Phase A1			Phase B					Phase A2		
Keyboarding	3	3	3	3	3	3	3	2	2	4	4	4
Writing name	5	5	5	5	4	4	3	2	2	5	5	5
Using fork/spoon	5	5	5	5	4	4	4	4	2	5	5	5
Putting on shirt	6	6	6	6	6	6	6	6	4	6	6	6
Drinking from cup	5	5	5	5	4	4	3	2	2	5	5	5

Scale found in Figure 2
BL = Baseline; * = missing data point

Child #4, the only one with a diagnosis of spastic diplegia, focused on bimanual keyboarding, writing his name, eating with a utensil, putting on shirt and drinking from cup with two hands. Caregiver assistance for three tasks was less during phase B than for both A phases (Table 4). For two of those tasks, caregiver assistance lessened from moderate help to no help but need for supervision during phase B. The RPS had only a minor impact upon bilateral keyboarding and putting on a shirt. His caregiver commented that his posture was more stable, and that he had greater endurance, less fatigue and greater success with tasks when he used the RPS. His caregiver also found that he was less frustrated and often pleased with his performance when he used the RPS. She pointed out, "*He is able to write short notes of 3 plus words. He has never done this before. He wrote 'I love you' in a note [to me]".* She noted in week 11, when he used the lap belt*, "Now I have to hold the paper, set him up posturally. Frequently, [he is] very discouraged".* Comments show that he was less messy eating and drinking during the weeks that he used the RPS.

Child #5 focused on removing lids from plastic containers, putting toothpaste on toothbrush, bimanual wheelchair wheeling, brushing hair and putting on coat. Again, caregiver assistance was less for three tasks during phase B compared with the A phases

(Table 5). The assistance required for the toothpaste and jacket tasks was not impacted by the RPS, although this child used more caregiver assistance for putting on her jacket during phase A2 than in the first 8 weeks. Caregiver comments don't fully explain this, although the caregiver points out that her daughter was able to get greater trunk extension and bring herself into an upright posture when she used the RPS. This caregiver also commented that during most tasks her daughter's posture was more upright, that her bottom stayed down on the seat, and that her reach was better when she used the RPS. At the end of Week 10, the caregiver commented about Child 5's wheeling abilities, *"Terrible – back to square one…bottom never on seat and nose over knees. [She needs] lots of verbal input."*

Table 5: Caregiver Assistance Weekly Ratings for Child 5

Tasks:	BL	Phase A1			Phase B					Phase A2		
Removing lid	6	6	6	6	5	5	5	4	4	5	5	5
Applying toothpaste	3	3	3	3	3	3	3	3	3	3	3	4
Propelling w/c	3	3	3	3	2	2	2	2	2	4	4	4
Brushing hair	5	5	5	5	5	4	4	4	4	5	5	5
Putting on coat	4	4	4	4	4	4	4	4	4	5	5	5

Table 6 : Caregiver Assistance Weekly Ratings for Child 6

Tasks:	BL	Phase A1			Phase B					Phase A2		
Brushing teeth	6	6	*	6	6	4	4	4	4	4	4	4
Brushing hair	6	6	6	6	4	4	4	4	4	5	5	5
Keyboarding	4	4	4	4	4	4	4	4	4	4	4	4
Turning pages	5	5	5	5	4	4	4	2	2	2	2	2
Moving dishes	3	3	3	3	3	3	3	3	2	3	4	3

Scale found in Figure 2

BL = Baseline; * = missing data point

Child #6 focused on brushing teeth, brushing hair on back of head, keyboarding accuracy and speed, turning pages of book and transferring dishes. The only task in which caregiver assistance lessened specifically during phase B was brushing hair (Fig. 9). Caregiver assistance for two tasks lessened over the 11 weeks, while assistance remained stable for the other two tasks. This caregiver found that her daughter was able to reach better, had better posture and less fatigue, and greater speed during task completion when she used the RPS.

In summary, the children in this study required moderate to total assistance for 77% of the target tasks at baseline and through phase A1. All children required total assistance for at least one task at baseline. Only Child #3 required no assistance with one task, the task of bimanual keyboarding. A reduction in the need for caregiver assistance began during phase B, when the RPS was used, for 17 of the 30 tasks (57%) across all six children during the study. For 9 tasks (30%), involving all six children, the caregiver assistance was lower during phase B, than the A phases. However, for another 8 tasks (26.7%), the caregiver assistance ratings were lower throughout the phase B and A2, than phase A1. Caregiver assistance did not increase for any task during phase B. Caregiver assistance remained stable throughout the three phases of the study for 9of the 30 tasks (30%) across all six children. Caregiver requirements increased by one point over baseline for one task for each of three children during phase A2, after the RPS was removed.

For 30% of the tasks, the amount of change in help needed by the child was reduced by more than one point on the caregiver assistance scale. For example, some children needed maximal assistance to start with, and gradually needed minimal assistance or just supervision after the RPS was installed. Caregiver assistance decreased by only one point for 20% of the tasks. This means that the caregiver may have helped do over half of the task for the child when the lap belt was used to start with, and helped with less than half of the task once the RPS was installed.

Daily Repositioning

Caregivers consistently maintained their daily log over the 11 weeks with only 7% of the repositioning data missing. The data gaps were spread across the weeks and across the sample. There was a clear visual trend indicating that five of the children were repositioned in their seating systems less frequently in phase B than in the phases A1 and A2. During phase A1 and A2, 80% of the children required repositioning 3 or more times/day, while Child #1 was typically repositioned 2-3 times/day. During phase B, 3 children were repositioned 0 to 1 time per day. Child #5 was only repositioned once per day for 76% of phase B. The caregiver for Child #2 reported that she was never repositioned during the study. Repositioning did not increase during phase B for any child. Child #1 was never repositioned while she used the RPS, but repositioned 3 or more times per day when she used the lap belt.

Discussion

This study found that the use of the RPS helped to reduce the amount of caregiver assistance required to complete bimanual or reaching tasks as compared with a traditional lap belt. The degree to which the RPS appeared to be directly responsible for reducing caregiver assistance was modest, as caregiver assistance was only less during Phase B for 30% of the tasks across all 6 participants. Caregiver assistance decreased by two or more points on the scale after the RPS was installed for 30% of the tasks, although for several tasks the reduction in caregiver assistance continued into Phase A2. Caregiver assistance did not increase when the RPS was used for any task for any of the children. The comments made by the caregivers during weekly interviews corroborate the ratings made on the caregiver assistance scale and help provide a fuller description of the child's performance. Overall, caregivers found that when the RPS was used their child had greater stability, could reach better, spilled less and was less messy, had greater endurance during task performance, and was less frustrated. In addition, 5/6 children were repositioned less when the RPS was used. This too would reduce the amount of time and effort required of the caregiver to help the child.

All participants and their caregivers rated improved task performance and greater satisfaction with task performance when the RPS was used compared with performance when a lap belt was used on their own wheelchair seating system (4). The postural stability gained while using the RPS appeared to help each child perform the manual tasks better, and lessened the child's need for caregiver help for some of those tasks. The RPS appeared to reduce caregiver assistance most strikingly for participants #4 and #5. For both children, caregiver assistance was less during phase B than during the A phases for 3 out of 5 tasks.

Caregiver assistance gradually decreased during the 5 weeks of phase B for child #4, the only participant with a diagnosis of spastic diplegia, suggesting that he gained greater task competency and required increasingly less help during the five weeks that he used the RPS. However, both children needed the same amount of caregiver assistance (and more assistance for one task) during phase A2 as they did during phase A1. This demonstrates that the RPS directly impacted upon their need for assistance, even though they may have benefited from practice and learning during the study. This finding is not surprising as we can assume that a child with spastic diplegia would have better bimanual skills than a child with spastic quadriplegia and could develop greater independence more quickly. This finding also suggests that rigid pelvic stabilization should be investigated more fully with children with spastic diplegia. These results are congruent with the caregiver reports of better performance with the tasks and satisfaction with performance of the tasks when the RPS was used (4).

In this study, fifteen distinct tasks were identified across the 6 children, demonstrating the impact of personal values, preferences and experiences on determination of successful outcomes (13). The within subjects, repeated measures design was appropriate considering the lack of homogeneity in skill level of the children assessed as appropriate for the RPS. All tasks involved either reaching or bimanual coordination, all of which were influenced by postural stability, as shown in the analysis of the COPM results (4). The tasks for which caregiver assistance lessened do not appear to differ much from the other tasks identified for the children in this study. Most of these tasks involved stabilizing an object with one hand while using the other hand to manipulate part of the object or a utensil. Some tasks involved reaching with one or both hands. Caregiver assistance was less when the RPS was used when 3 children brushed their hair, the task involving the most reaching, and for 3 children opening containers, which involves opposing bimanual control.

From a developmental perspective, children within the age range of those in this study (8 -12 years), are typically independent with the tasks identified by study participants, and are developing greater proficiency with such skills as handwriting and dressing. In this study, caregivers reported at baseline that the children either had difficulty doing the identified tasks or had never been expected to do some tasks without caregiver assistance. Kellegrew (14) makes the point that children with special needs require both the skills and the opportunities to use these skills in order to demonstrate their independence in daily occupations. In this study, the identification of 5 tasks for each child made them a focus for eleven weeks and consequently the caregivers not only provided opportunities for the children to do the tasks, but also expected the children to participate more fully in doing the tasks. This may also help to explain the reduction in caregiver assistance, particularly when this reduction was sustained through the remainder of the study.

The combination of the adapted Caregiver Assistance Scale, (11) and the COPM was a useful method for evaluating the impact of assistive technology upon a child's functional abilities and needs for assistance. It enabled the researchers to link the function of the assistive technology (e.g., the goal for the RPS to improve sitting stability to enable bimanual function) with technology users' functional independence (e.g., to do more of the bimanual tasks without needing help). This strategy for evaluating functional independence may be of value when studying the impact of other assistive technologies on the abilities of persons with physical disabilities. The cost effectiveness of assistive technologies could be validated if caregiver assistance is reduced when the technology is used.

Conclusions and Recommendations

Rigid pelvic stabilization is a less commonly used method for securing children in wheelchair seating systems (1), but appears to be a viable option and can allow children to develop the functional skills necessary for improving functional independence (4). Although the impact of the RPS on caregiver assistance was not uniform across all study participants and all tasks, two clinically important outcomes were observed. Caregiver assistance was less for 30% of the tasks specifically when the RPS was used, and the degree of reduction in assistance for those tasks ranged from one to three points (e.g., from needing maximal or moderate assistance to needing minimal assistance to complete the task). A small sample was used in this study, and replication of this work would contribute to further validation and generalization of the findings.

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4

Chapter

Effect of Adaptive Seating Devices on the Activity Performance of Children with Cerebral Palsy

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Abstract

Objective: To evaluate the short-term impact of 2 adaptive seating devices on the activity performance and satisfaction with performance of children with cerebral palsy (CP), as observed by their parents.
Design: Baseline-intervention-baseline study.
Setting: Homes of participating families.
Participants: Parents and their children (N=30), mean age of 4 years 6 months, with Gross Motor Function Classification System level III and IV CP participated.
Intervention: Two special purpose seating devices – one for sitting support on the floor or on a chair, the other for postural control on a toilet.
Main Outcome Measures: Changes in activity performance and satisfaction were measured through parent ratings on the Canadian Occupational Performance Measure. We interviewed parents biweekly using the Home Activity Log to describe and explain their child's activity performance during the 3 study phases.
Results: Parents identified 139 activity performance issues (4.6 per child); 58.3% in self-care, 34.5% in play, and 7.2% in socialization and quiet recreation. We used paired t-tests to demonstrate significantly improved performance and satisfaction with self-care and play activities when the children used the adaptive seating devices during the 6-week intervention phase. Three themes arose from the analysis of comments made by parents during Home Activity Log interviews: adaptive seating can have an enabling influence on child; caregivers and family find adaptive seating useful; the adaptive seating devices did not meet every family's needs.
Conclusion: Parents reported that their young children with CP were more able to engage in self-care and play activities when using specific adaptive seating devices in their home. Parents indicated that their child's activity performance decreased after the seating devices were removed from their home.

Key Words: Activity; Assistive technology; Child; Outcomes; Rehabilitation.

List of Abbreviations

APIs	Activity Performance Issues
CP	Cerebral palsy
COPM	Canadian Occupational Performance Measure
FIATS	Family Impact of Assistive Technology Scale
GMFCS	Gross Motor Function Classification System

Introduction

CP is a non-progressive lesion of the immature brain that results in impairment of movement and postural control, and is the most common physical disability in childhood.[1] Many young children with CP cannot sit without support[2,3]. Thus, physical and occupational therapists routinely prescribe adaptive seating devices for them, to promote their function and improve their developmental capabilities.[1-4]

A number of studies have evaluated sitting posture and various features of adaptive seating devices for children with CP, and 3 authors have reviewed this literature.[2,3,5] Roxborough[2] found that postural control, pulmonary function and psychologic skills improved with some adaptive seating interventions. However, she found little evidence for the effect of seating on self-care. Harris and Roxborough[5] concluded that seating interventions that stabilized the pelvis and increased the seating base of support optimized postural control. The review by Stavness[3] examined how sitting affected upper extremity function. She found that upper extremity function was better when children sat in an upright versus a reclined position, with a neutral to slightly forward orientation of the seat.

Harris and Roxborough[5] recommended that future studies should examine the impact of adaptive seating on children's functional abilities in their daily life. This is important because a primary goal for therapists who prescribe adaptive seating is to provide the child with CP with a safe, stable seated posture from which the child can engage in controlled upper extremity movements to enable the child to actively engage in many daily activities, including play and self-care.[3,6] Furthermore, contemporary models of rehabilitation and family-centered services recommend that rehabilitation practice and research should address the activity performance and participation of children with CP within family life, as outcomes of interest.[7-9]

Despite widespread clinical use, little is known about the effect of seating technologies on the activity performance of young children with cerebral palsy at home. To address this gap in knowledge, we conducted a study to examine the impact of 2 seating devices on important, parent-identified activity performance issues at home. We asked the question: "Do special purpose seating devices used in the home improve the activity performance of young children with GMFCS level III and IV CP[10] as measured by the COPM?"[11]

Methods

The present study was part of a larger project that examined the measurement properties of the FIATS.[12] We received ethical clearance from the Research Ethics Board at Bloorview Kids Rehab in Toronto, Canada.

We used a within-subject A1-B-A2 design to study the influence of postural control devices for seating on children's activity performance in daily life within their homes. The first baseline period (A1) lasted for 3 weeks, followed by a 6-week seating intervention period (B), then another 3-week return to baseline period (A2), as shown in figure 1. This design eliminates between subject effects by using parents and their children as their own controls. While a crossover protocol would have been a stronger design, this design was chosen for the larger measurement study.

The baseline period of 3 weeks was considered a sufficient length to demonstrate stable functional behaviors.[13 (p. 186)] Based on our previous experience, an intervention period of 6 weeks provided adequate time for the children and their family to adjust to using the seating technologies and to establish regular activity routines.[14]

Participants

Thirty parents and their young children (mean age of 4y, 6mo; range 2y, 6mo to 6y, 7mo), who were clients of 3 children's rehabilitation centers in south-central Ontario, Canada, agreed to participate in this study. All parents provided informed consent for themselves and their children. Eligible families included children who had a primary diagnosis of CP with a functional status defined by the GMFCS level III or IV.[10] This functional level meant that each child had some ability to move around on the floor (eg, by rolling or creeping), but had difficulty in maintaining floor sitting, or required trunk support to maximize hand function when sitting on a chair.[10] We found that our sample size exceeded the number of participants needed for a power of 80% and α=.05 (2 sided), when we examined data from a comparable within-subjects study wherein the COPM was used to evaluate performance differences with and without an adaptive seating intervention.[14] Details on recruitment procedures can be found in an earlier publication.[15]

While we recruited children who did not use special purpose seating devices for floor sitting, chair sitting, or toileting, most participants did use some form of assistive technology in the home at the time of enrollment in the study. All children either used a wheelchair or a stroller in their home. Parents also reported that they positioned their children by using an assortment of pillows, or the help of family members, or by using modified juvenile seating systems such as a highchair or a car seat. Some families also used homemade devices such as modified potty seats and corner seats to provide seating support.

Intervention

In the study, we supplied the Flip2Sit activity seat[a] for floor sitting and table level activities, the Aquanaut toileting system[a] for toileting and grooming in the bathroom. Both devices are intended to provide sitting support for children with CP who have postural instability. Clinicians and parents have reported that both devices provide appropriate postural support in sitting to help young children with CP participate in a variety of important home activities.[16,17] We also provided families with a simple, self-standing bed tray[b], so children could play on an elevated surface while they sat in the activity seat at floor level.

Outcome Measures

Canadian Occupational Performance Measure.[11] The COPM is a criterion-referenced outcome measure that has demonstrated responsiveness to change over time,[14,18,19] and has been found useful for evaluating the effectiveness of assistive technologies.[14,20,21] It has been successfully used with parents for the evaluation of children's occupational performance problems or issues as identified by the child's parents,[22] and to evaluate the effect of adaptive seating devices for children with CP.[14] The reliability and validity of the COPM is well documented.[11,18] A change of 2 or more points on the performance or satisfaction with performance scales on the COPM is considered to be a clinically important change.[11]

We chose the COPM as it is administered through a semi-structured interview and allowed us to ask each parent to identify up to 5 important problems that their child was experiencing in the areas of self-care, play and leisure within their daily life at home.[18] In order to evaluate the impact of the seating devices, we adapted the COPM questions and asked the parents to focus on activities that the child required seated postural control to do, and which were difficult for the child to do. Consequently, we identified these as activity performance issues, rather than occupational performance issues as parents had targeted specific aspects, or steps of the occupation that their child had difficulty doing.

Home Activity Log Interview. We developed the home activity log (HAL) interview (Appendix 1) for this study to monitor, biweekly, the parent's perspectives about their child's activity performance over the 12-week study. Parents were asked to describe any changes that they observed in their child's daily behaviors and activity performance in the 3 categories of self-care, play and quiet recreation/leisure. They were also asked how the seating devices influenced the activity performance of their child during the intervention phase. We collected these perspectives from parents to help us interpret the COPM change scores.

Data Collection

One of 2 experienced occupational therapists (who had 12 and 20 years experience with children with physical disabilities, respectively) visited each parent and child in their homes at selected times to administer the outcome measures. The COPM was administered 4 times in total; during weeks 1 and 3 (the beginning and end of the baseline period), during week 9 (at the end of the 6 week intervention period), and during week 12 (at the end of the second baseline period), as shown in figure 1. It was impossible to blind the occupational therapists due to the nature of this intervention.

On each administration, the parent used the 10-point COPM scales to rate their child’s performance and satisfaction with their child’s performance on each of the activity performance issues that they had identified during the baseline COPM interview during week 1. On the performance rating scale, a “1” meant that the child was not able to do the activity whereas, a rating of “10” meant that the child was able to do the activity extremely well. On the satisfaction scale, a rating of “1” meant that the parent was not satisfied at all with the child’s performance whereas a rating of “10‟ meant that the parent was extremely satisfied with the child’s performance of that activity.

The study therapist administered the home activity log every other week either through a phone interview or in person during the home visit. The study therapist used the home activity log as a guide to interview parents and record changes in the child’s activity performance, and any changes in family routines over the proceeding week. The therapist recorded the parents’ comments during the interview.

Figure 1: Research Design Schedule

Weeks											
1	2	3	4	5	6	7	8	9	10	11	12
Pre-Intervention [A1]			Intervention [B] (seating systems used)						Post-Intervention [A2]		
COPM HAL		COPM HAL		HAL		HAL		COPM HAL	HAL		COPM HAL

The therapist delivered and set up the study devices for each family at the end of the first baseline phase. Parents were shown how to use the devices with their child and given precautions and safety instructions. Parents were also given the device owner’s manuals, and were asked to read them to ensure they understood how to use the devices. Families used the study devices for 6 weeks and the therapist retrieved the devices at the end of the intervention phase, at the end of week 9. Once the measures were administered a final time, the research therapist offered the 2 devices to parents free of charge to show our appreciation of their participation in our study.

Data Analysis

The COPM data were aggregated, as others have done[19,23,24], into 3 categories: self-care, play, and socialization/quiet recreation. Parametric statistics were used as recommended in the COPM manual,[11] and based upon examination of the distribution of our results. We used paired t-tests to compare mean scores between weeks 3 and 9, and between weeks 9 and 12. We used a Type I error rate of $\alpha=0.05$ (2-sided) with Bonferroni correction for multiple testing for the performance and satisfaction t-tests. With 16 tests, this led to a statistical significance being defined as a p-value $< .003$ for any of the t-tests.

We collated the home activity log data from 6 data collection points and then conducted a thematic analysis through an iterative process of sorting the data into common themes. We integrated the interpretation of home activity log and COPM results using the, 'follow a thread' strategy described by Moran-Ellis et al [25] which involved an iterative examination of common threads across both datasets. This process helped us to explain and further understand the families' experiences with the seating interventions and their COPM ratings.

Results

COPM Results

The 30 participating parents (29 mothers, 1 father) each identified 3 to 5 activity performance issues for their children. We then organized the 139 activity performance issues (average of 4.6 activity performance issues per family) into the 3 categories. All 30 parents identified activity performance issues in self-care (58.3% of the activity performance issues), while 27 parents identified that their child had challenges playing (34.5% of the activity performance issues), and only 6 parents identified activity performance issues in socialization and quiet recreation (7.2% of the activity performance issues). Figure 2 provides examples of activity performance issues reported by parents in each category.

The aggregate mean scores for each COPM category and the total are shown in table 1. The mean scores shown for weeks 3, 9, and 12 are from the baseline, intervention, and return to baseline (or post-intervention) phases (A1, B, and A2). The performance scores on the COPM increased by an average of 4.6 (on a 10-point scale) during the intervention phases, while the satisfaction scores on the COPM increased by an average of 4.9. The results of paired t-tests, mean differences, and the 95% confidence intervals around the differences (see table 1) confirm that the effect of the seating intervention on parent ratings of the children's activity performance resulted in significant changes in performance and satisfaction scores between intervention phase and 2 baseline phases overall and within the self-care and play activity performance issues categories. The t-test results were not significant for the socialization and quiet recreation performance and satisfaction scores

Figure 2: Categories and Examples of API's identified on COPM

Category	Examples of API's
Self-care	self-feeding; eat at table with family; drink from a cup; eat meals at restaurant/relative's/friend's; use the toilet; sitting independently on toilet; brushing teeth; taking shoes and socks off; take off upper garments in dressing; sit up properly for dressing and undressing
Play	sitting on floor to play; holding/playing with toys; colouring, writing, playing, playing games, using computer while sitting at table;
Socialization and Quiet Recreation	sitting and socializing at table; sitting up and watch TV; reading a book; turning pages of book

results were not significant for the socialization and quiet recreation performance and satisfaction scores when comparing week 3 to 9 and week 9 to 12. Parents rated their children's performance of most of the activities, and their satisfaction with their child's performance as much greater when the children used the study devices, than during the baseline and post-intervention weeks, when their children did not use the devices.

Home Activity Log results

Three themes arose from the thematic analysis of sorted data. The findings largely reflect the parents' views about the impact of the study devices, because there were 2 additional questions asked during the intervention phase.

Theme 1: Adaptive seating can have an enabling influence on child.

Most parents reported positive benefits from using the adaptive seating devices, including that their child was sitting better, was doing more, was more engaged, and was doing the activities identified on the COPM for longer periods of time when using the adaptive seats during the intervention phase. Several parents reported that their child's skills improved, while others reported that their children were happier and more eager to sit and do activities and were now able to engage in face-to-face social interactions resulting in more socialization with members of the family and with friends. After the devices were removed at the end of the intervention phase, several parents reported that their children became more passive, or were less interested and less engaged; while other parents described their child as less social and less interactive.

Table 1: Paired Comparisons of COPM Total and Category Scores

Activity Performance		Mean Scores				Mean change (99% CI) p-value	
Categories		Week 1	Week 3	Week 9	Week 12	Wks 3-9	Wks 9-12
Self-care	Performance	2.37	2.13	7.48	2.14	5.38 (3.80 – 6.96) p<.001**	-5.34 (-6.98 – -3.71) p<.001**
	Satisfaction	2.67	2.23	8.07	2.21	5.79 (4.08 – 7.51) p<.001**	-5.86 (-7.69 – -4.03) p<.001**
Play/School	Performance	2.35	2.10	6.21	2.50	4.11 (2.21 – 6.00) p<.001**	-3.71 (-5.62 – -1.81) p<.001**
	Satisfaction	2.57	2.18	6.57	2.15	4.39 (2.28 – 6.50) p<.001**	-4.17 (-6.39 – -1.97) p<.001**
Social/QR	Performance	2.00	2.83	6.33	2.83	3.50 (3.23 – 10.23) p=.076	-3.50 (-9.27 – -2.27) p=.058
	Satisfaction	2.50	3.33	7.17	2.50	3.83 (3.11 – 10.77) p=.090	-4.67 (-10.80 – -1.46) p=.028
Mean score	Performance	2.31	2.22	6.83	2.33	4.61 (3.14 – 6.09) p<.001**	-4.50 (-6.01 – -2.99) p<.001**
	Satisfaction	2.60	2.35	7.27	2.36	4.92 (3.39 – 6.45) p<.001**	-4.92 (-6.66 – -3.18) p<.001**

** statistically significant

Note: The confidence intervals (CI's) are around the differences used in the paired t-tests

Theme 2: Caregivers and family find adaptive seating useful.

During the intervention phase parents found the seating devices convenient and easy to use, and many reported that their child needed less caregiver help. Nearly one-quarter of the parents described how their child was able to now join the family for meals, games and social interactions. The comments made by one mother reflected how several parents felt about being able to sit facing their child, when using the study devices, rather than holding their child from behind. She noted that she had more eye contact and more communication when she played with her child. She felt she understood his wants and needs faster because she could see his face.

Parents also commented favorably about the portability of the activity seat, saying they used it on various chairs within their home, such as kitchen or computer chairs; they took the seat with them when visiting family and friends in their homes, and they used it successfully at restaurants. For example, one parent noted that they take the activity seat everywhere including restaurants, and think it's great. For some of those who used the activity seat for quiet recreation, they described feeling safer leaving their child to watch television or listen to music.

Theme 3: The adaptive seating devices didn't meet every family's needs.

A few families reported little to no change in how their child completed the activities identified on the COPM during the intervention phase. The most common complaints were that the activity seat did not provide enough support or that it lacked the stability their child needed on the floor. These parents reported that they supervised their child more closely when using the activity seat. A few parents said that their child complained about the straps on the activity seat and did not like to be constrained, preferring instead to be mobile.

Descriptive Results

A descriptive analysis of the parent interviews showed that 26 children used the activity seat and 24 children used the toileting system over the entire intervention period. The toilet seat was used primarily for self-care, including toileting, grooming, and brushing teeth; whereas the activity seat was used for play, mealtime, and social or leisure activities. The activity seat was used on the floor or on a variety of chairs, including kitchen/dining room/office chairs, couches or restaurant chairs. For families who did not use both study devices, their principal reasons were that 1 or both devices did not provide sufficient postural support for their child and/or the child rejected the device.

When offered the devices at the end of the study, 25 families (83%) kept at least 1 device, while 19 (63%) families kept both devices. Four families (13%) kept the activity seat and returned the toilet seat, while 2 families kept the toilet seat and returned the activity seat. Five families (17%) returned both devices.

Discussion

Our COPM results indicate that statistically and clinically significant improvements in activity performance and performance satisfaction were achieved when the children used adaptive seating devices in their homes for specific self-care and play activities. These findings were supported by the views expressed by their parents during the home activity log interviews.

When the study devices were removed from their homes during the post-intervention phase, the children's activity performance and parents' satisfaction with their child's performance returned to baseline levels on the COPM, and parents described their children's loss of abilities on the home activity log. The magnitude and precision of the change scores on the overall, self-care, and playing activities on the COPM suggest that the removal of these devices had a negative effect that was both statistically significant and meaningful to parents.

It is also important to note that the mean performance scores for self-care and play were less than 3 points on the 10-point scale at weeks 3 and 12, which demonstrates that the children were not able to do the activities very well without the seating devices. Whereas they were able to do the activities quite well with a self-care mean score of 7.48 and play mean score of 6.21, when they used the seating devices, as measured in week 9. Our study provides preliminary evidence that adaptive seating interventions can be used successfully to help children with GMFCS level III or IV CP to attain a supported sitting posture, which enabled them to perform a variety of childhood activities more successfully within their daily life at home.

Although the point estimates of the true difference scores between the intervention and baseline phases for performance and satisfaction were greater than 2 for the category of quiet recreation and socialization, which is considered a clinically significant change,[11] our corrected confidence limits were too large to infer a statistical effect. We do not believe that we lost significance by using a parametric versus a nonparametric approach to examine the differences in scores. The loss of precision in this estimate was because parents only reported 10 activity performance issues overall. Consequently, we could not conclude that the study devices made a significant difference to COPM performance and satisfaction scores for this category.

The activity performance issues identified by the parents demonstrate that parents focused on very specific functional challenges within the child's daily life, many of which directly involved sitting, and others that were greatly influenced by the child's ability to sit. For example, most of the self-care and play activities involved manual manipulation of materials such as toys, feeding and grooming utensils. The seating interventions appear to have enabled most children to gain a stable, supported sitting posture, from which they could use their hands to engage in various activities.

While we cannot make inferences about the impact of the seating devices on hand function, our findings do support the clinical assumption that achieving a stable seated posture from a seating intervention has an enabling effect on a child's hand function.[4] Our results build upon the findings from studies reviewed by Roxborough[2] and Stavness[3], which demonstrated how specific seating interventions improve postural control and upper extremity function.

Our results are also consistent with an earlier study, not included in the Stavness review[3], which examined the clinical assumption that a stable pelvis leads to improved hand function. Reid et al[14] used the COPM to evaluate the impact of a wheelchair mounted rigid pelvic stabilizer on bimanual task performance for 6 school-aged children with CP, using a within-subject A1-B-A2 design over 11 weeks. They found that participants and their parents agreed that the child's bimanual task performance was better when the postural control device was used to stabilize the child's pelvis, compared with a lap belt. Satisfaction ratings were also higher during the intervention phase.

Our home activity log findings provide context and explanation for the COPM outcomes. During the home activity log interviews, parents described the changes in how some activities were performed over the 3 phases of the study. It was evident that for many families, the child was not doing some activities, or was doing those activities very differently prior to the introduction of the seating intervention. Then, during the intervention phase, the child became accustomed to being able to do an activity and both children and their parents wanted to continue that activity after the study device was removed.

For example, many children were using diapers rather than a toilet prior to the introduction of the toileting device. Some families reported that their children were somewhat successful in using the toilet while positioned on the toileting device. During the post-intervention phase, some parents expected their children to continue to do that occupation (eg., toileting) using the method adopted during the intervention phase. However, without the study device, parents then had to hold their child instead. The absence of the device made it more difficult to perform this activity because the way in which the child was supported on the toilet was different. This was reflected in the lower performance and satisfaction scores on the COPM at the end of the final phase.

These findings lead to speculation that, given a longer intervention phase, the children could be exposed to and given more opportunity to engage in activities that were previously not accessible to them because of their inability to sit independently. Because the activity seat is multi-purpose, portable, and easy to set up and use, several families reported using it in a variety of ways during the intervention phase. For example, some families took the activity seat to restaurants or relatives' homes for meals, while others used it outdoors for play. Future research could be designed to explore the impact of this and other seating devices over longer periods than we used in our study. Lenker and Paquet[26] propose that the impact of assistive technology is a predictor of future use of that technology. Based on their arguments, we would expect that the children and families from our study would continue to find the seating devices useful over time, particularly if families find the benefits outweigh any shortcomings in the technology itself, and the ease of use.

While our results were largely positive, a few families found that 1 or both seats did not help their child. Although our research therapists evaluated the appropriateness of the devices for the children, the parent or child rejected the device(s) part way through the intervention phase. Neither level of acuity of GMFCS level nor age were a factor here. Further, some families had limited space available in their home (eg., lived in a small apartment, or had a crowded home) and they could not easily store the device when it was not in use by the child.

Study Limitations

Our study has several limitations. The baseline-intervention-baseline design is more vulnerable to measurement error (bias) than a randomized controlled trial or a crossover design. Bias may have been inadvertently introduced into the parent interviews since the research therapists were aware of the study objectives. Parents were not aware of the study objectives; however, they may have made their own assumptions, which could have influenced them to respond in ways to make it appear that the impact of the devices was greater than it actually was. However, our results are consistent with the findings of our broader study where we used the FIATS and the Impact on Family Scale to measure the impact of the study devices on the lives of children and their families.[15]

The findings from our study may not generalize to children with differing physical disabilities nor those who live in different geographic regions, as our respondents were parents of children with CP who lived within or close to a large metropolitan city.

Implications for Clinical Practice and Research

Two important implications for clinical practice and future assistive technology research arise from our study. First, during recruitment for the study we learned that there were many children who were not using adaptive seating devices in their homes. We suspect that this may be due to several factors: many therapists in our region provide services primarily to children in schools, and may not be mandated to assess or make recommendations regarding a child’s home environment; families may not be aware of the adaptive seating options available to them for their home; alternative ‘ad-hoc’ approaches were being used by families (eg, using an assortment of pillows to provide the child with postural support on the floor); and financial support for special types of assistive technology, such as our study devices, is not available from traditional government sources. This finding also raises questions about how aware therapists are about seating technologies that could be used to support functional outcomes for children in their homes.

Secondly, we found the COPM to be a very useful and responsive outcome measure for detecting families’ perceptions of meaningful change in their child’s activity performance when examining the impact of adaptive seating interventions. These clinically meaningful results are consistent with the findings of our study using the FIATS as a primary outcome measure of the impact of the devices on child and family life[15] and with previous studies where the COPM was used to demonstrate the effectiveness of assistive technology devices on children’s activity performance and on their parents’ level of satisfaction with this performance.[14,21] The COPM also enables the clinician prescribing adaptive seating interventions to use a family-centered perspective[9] as parents and/or children evaluate self-identified occupational or activity performance issues that matter to them. Our experiences with the COPM add to the growing interest in the benefits of using individualized outcome measures, such as the COPM in assistive technology research.[27,28]

Conclusions

Parents reported that their young children with CP were more able to engage in self-care and play activities when they used the study seating devices in their homes during the intervention phase. Parents were also more satisfied with their child's activity performance when the study devices were used, and described the enabling influence provided by the study devices, and how the devices helped in their interactions with and care of their child. A few parents, however, felt the study devices were not well suited to their child's needs. Our study findings reinforce the need to remind rehabilitation technology practitioners to be mindful of the match between the goals and circumstances of individual children with CP and their families, and the opportunities for functional gains afforded by adaptive seating devices.

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Suppliers

a. Otto Bock HealthCare Canada Limited, 5045 South Service Rd. Suite #201, Burlington, ON Canada, L7L 5Y7.

b. Inter IKEA Systems B.V. Olof Palmestraat 1, NL-2616 LN Delft, The Netherlands.

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Appendix 1: Home Activity Log (HAL) Interview

Activity Performance Areas	**Activity – In the past week, please tell me how…**
Play	... your child played while seated at home. For example, did s/he actively play more or less with friends/ family members, change how s/he did tabletop or floor level activities such as colouring, or change how s/he played with objects such as toys or games?
Self-Care	... your child participated in self-care while seated at home. For example, did s/he actively participate more or less during activities such as getting dressed, brushing teeth, or using the toilet?
Leisure	... your child participated in leisure while seated at home. For example, did s/he actively participate more or less in recreational activities such as singing, listening to music or watching TV?
Were there any changes in your family routines or caregiver routines that changed your child's activities at home over the past two weeks? (e.g., holidays, visitors, special events, illness …)	
Intervention Phase Only	
Please tell me how using Aquanaut influenced how you, your child, and other family members did activities in the bathroom over the past two weeks.	
Please tell me how using Flip2Sit influenced how you, your child and other family members did activities over the past two weeks.	

2

Section

STUDIES TO EXAMINE THE IMPACT OF ELECTRONIC AIDS TO DAILY LIVING ON ACTIVITY PERFORMANCE AND QUALITY OF LIFE

Chapter 5: **Impact of electronic aids to daily living on the lives of persons with cervical spinal cord injuries**

Chapter 6: **Development of the measure of control using electronic aids to daily Living**

Chapter 7: **Electronic aids to daily living and quality of life for persons with tetraplegia**

5

Chapter

Impact of Electronic Aids to Daily Living on the Lives of Persons with Cervical Spinal Cord Injuries

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With funding from the Ontario Neurotrauma Foundation
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Abstract

Structured interviews were used to evaluate the impact of electronic aids to daily living (EADL) on functional abilities and psychosocial well-being. The participants included 32 adults (26 men, 6 women; mean age of 39 years) with cervical spinal cord injuries. The experiences of 16 EADL users were compared with a control group of 16 nonusers, on the Functional Autonomy Measuring Scale, the Lincoln Outcome Measures for Environmental Controls, and the Psychosocial Impact of Assistive Devices Scale. Results show EADL users had significantly better performance ($p< .05$) than nonusers for instrumental ADLs, and for 75% of 12 daily tasks. Many nonusers had hands-free control of phones only, while users had control over many other household devices, which optimized their independence. The psychosocial impact of this technology was very positive for competence, adaptability and self-esteem. In conclusion, functional abilities were greater for a variety of daily tasks and psychosocial impact was positive when EADL were used.

Key Words

Assistive Technology, Functional Abilities, Psychosocial Wellbeing

Introduction

Electronic aids to daily living (EADL), also known as environmental control units, allow people with severe physical disabilities to control aspects of their home, school or work environment. These aids provide alternative access to devices such as telephones, personal entertainment centres, computers, home security systems, lights and thermostats by means of single switches, voice, or serial input through a computer (1, 2). Electronic aids can enable persons with high-level cervical spinal cord injury (SCI) to do many daily tasks independently, such as change channels on their TV and adjust their home heating system. Without the use of EADL, these individuals are typically dependent upon others for help with most daily activities (3).

Since the 1960's when electronic aids were first made available, the many claims about their benefits have been largely a matter of opinion (4, 5). The research that has been conducted is largely descriptive of the experiences of EADL users and can be categorized into four main areas: 1) the perceived benefits of EADL; 2) utilization of EADL; 3) activity patterns; and 4) impact of EADL on caregivers.

In three studies, EADL users reported that increased independence was a major benefit from using their system (3, 6, 7). The results of eight case studies showed that after a 2-week trial of EADL, all participants perceived an increase in their independence in specific functional areas in which they desired greater control (6). A group of 16 EADL users reported that the experience of control within their home environment, which was afforded by their system, enhanced their feelings of self-worth and self-confidence (7). A group of 29 users with high-level SCI ranked communication, security and recreation as the most important benefits, the most important functions being the use of the television and room lights (3).

Similarly, studies of EADL utilization have shown that the aids are used frequently to operate the phone, TV, stereo, fan and lights (8-10). In another study, the activity patterns of 7 users and 13 nonusers were found to differ, while locus of control was not differentiated between the two groups (11). Users engaged in more educational activities, phone calls and in travelling, whereas nonusers stayed at home and engaged in passive recreational and quiet activities, such as watching TV and listening to the radio. Strikingly, Cowan and Turner-Smith (12) found that 94% of 83 EADL users who responded to their survey reported that they use their EADL daily.

In an investigation of EADL impact on 20 EADL users with a degenerative neuromuscular condition, the perceived impact on quality of life was positive, and was greatest in the area of functional competence with daily activities (13). These findings were stable over time. In addition, there was striking similarity between the anticipated impact of EADL by a comparison group of 20 nonusers with the real impact as rated by device users. In this same study, the users were most satisfied with the simplicity of use and multipurposefulness of the devices and the impact of EADL on their personal safety (14).

Caregivers and users both agree that this technology has a positive impact upon caregivers. Caregivers reported that EADL usage reduced the demands made upon them, and improved the disposition and attitudes of care recipients, which, in turn, had a positive influence on caregivers themselves (9, 10, 15). In a study of 15 institutional residents, EADL usage was estimated to reduce attendant services by an hour per day per resident, and was found to decrease resident frustrations, which consequently improved the morale of attendants (9). Caregivers and EADL users expressed confidence that users could be left unattended for periods of time, as the EADL could be used to summon help and to control the environment for comfort and security (3, 7, 10).

Purpose of Study

Clinicians, service providers and third-party payers need evidence about the outcomes of assistive technology interventions in order to select and provide the best services for their clients (16). While earlier research provides support from the perspective of EADL users about the benefits and utilization of EADL, the impact of EADL on functional and psychosocial outcomes has not been adequately addressed through the comparison of EADL users with a group who do not use this technology. Therefore, the primary purpose for this study was to investigate the impact of EADL on functional performance within the home, and the psychosocial impact of this technology by comparing the experiences of a group of EADL users with a comparable group of nonusers living in Ontario, Canada.

Methods

Design

Two groups of participants, EADL users and nonusers, were compared on measures of the psychosocial impact of EADL and the impact of EADL on functional abilities. A comparative study design was chosen, rather than a pre-post design as it was clear from studying the databases of the EADL service providers in our region that there were not enough EADL prescriptions made annually for clients with cervical spinal cord injuries to make it feasible within our study timelines to recruit an adequate sample size prospectively and to randomize participants to groups.

Sample

Thirty-two participants with a cervical SCI (mean age 39.7 years) were recruited from 2 large urban centers in southern Ontario, Canada, and agreed to participate in this study through informed consent. All participants had spinal cord lesions at the level of C6/7 or higher, with the exception of one individual with Guillan Barre syndrome who had a functional level comparable to that of a person with a C4 level SCI. Among the participants, 16 were experienced EADL users, and 16 were non-EADL users; all participants were post-rehabilitation by at least one year.

Persons were included as EADL users if they used an electronic unit to access and control at least two devices, such as an emergency alert device, specialized telephone, door openers, lights or stereo. The EADL users had a minimum of six months experience using their EADL system. We categorized persons as nonusers if they had no specialized equipment to control electronic devices in their home, or had only one or two electronic aids each controlling only one device, such as a specialized telephone or a remote control door opener.

Measurement

We used a combination of three tools to measure participants' functional abilities, and the psychosocial impact of EADL. Each measure is described below.

1) The Functional Autonomy Measuring Scale (SMAF) (17) measures functional abilities in five domains: activities of daily living (ADL), mobility, communication, mental functions and instrumental activities of daily living (IADL). Each item within each of the five domains is given a disability score on a 5-point scale that ranges from 0 (independent function) to –3 (dependent). A half score (0.5) is included when the item can be performed independently, but with difficulty. A total disability score is calculated out of a possible total of –87, and subscores are calculated for each domain. The lower the total SMAF score or domain score, the more severe the level of disability. This tool has primarily been used in geriatric settings and studies have demonstrated that it is valid, reliable and can discriminate levels of disability (17, 18).

2) The Lincoln Outcome Measures for Environmental Controls and Audit of Installation Quality (LOMEC) (19) is an evaluative measure of functional abilities specific to the functions enabled by EADL. For this study, we slightly modified the LOMEC to ask each participant, both users and nonusers, to rate their ability to perform all 12 listed tasks. Three detailed functional tasks in each of four categories of home security, communication, comfort and leisure/work are listed.

Additionally, EADL users rated the acceptability and availability of their EADL system. The rating scales are ordinal and are individualized for each functional item using a 3-point scale. In summary, the zero meant "unable to perform the task, and needs not met", the 1 meant "partially able to perform task; needs partially met", and the 2 meant "fully able to

Table 1: Demographic summary

		EADL Users *(n=16)*	Nonuser *(n=16)*
AGE	Mean	39.7 years	39.8 years
	Age Range	21-67 years	23-60 years
GENDER	Male	12	14
	Female	4	2
LEVEL OF SCI	C3/4 and above	4	2
	C4/5	9	6
	C5/6	2	7
	C6/7	1	1
INJURY TYPE	Incomplete	1	6
	Complete	15	10
EDUCATION	Grades 7-11	2	3
	High school graduate	3	4
	College or University	11	9
CURRENT VOCATION	Unemployed	3	7
	Self employed	2	1
	Professional	5	2
	Unskilled Worker	0	0
	Student	4	2
	Volunteer	1	1
	Retired	1	3
LIVING SITUATION	Alone (apartment or house)	8	5
	Alone with family nearby (apartment)	2	0
	With roommate (apartment)	1	0
	With family (house or apartment)	4	9
	Assisted living facility	1	2
ASSISTANCE	Mean hours of attendant care/day	6.6 hours	6.75 hours
	Range of hours of attendant care/day	3 – 15 hours	4 - 13 hours

perform task; needs met". Thus, higher LOMEC total or subscale scores mean the respondent has greater ability and independence doing those tasks.

The functional items and the items pertaining to acceptability and availability of the EADL system are described in Figure 1. Examples of functional test items are included in Figure 2. Similarly, the degree of acceptability and system availability was recorded on a 3-point scale. Comments were recorded to provide context to the scores provided.

At the time of this study, no information was available or published about the psychometric properties of this version of LOMEC, and no alternatives had been published or used as a standard previously. However, since then we made revisions to the LOMEC. We established that it has good content validity, internal consistency and test-retest reliability through a study with 36 persons with cervical spinal cord injuries (20). This new measure shows promise as a clinical outcome measure.

3) The Psychosocial Impact of Assistive Devices Scale (PIADS) (21, 22) is a 26-item, self-rating questionnaire designed to measure user perceptions of how assistive devices affect quality of life. The PIADS describes user perceptions along three dimensions: Adaptability (the enabling and liberating effects of a device); Competence (the impact of a device on functional independence, performance and productivity); Self-esteem (the extent to which a device has affected self-confidence, self-esteem and emotional well being). Scores can range from –3 (maximum negative impact) through zero (no perceived impact) to +3 (maximum positive impact).

Studies have shown that the PIADS is a reliable, valid, and responsive measure, with good clinical utility (23, 24). It was an informative and sensitive measure in a study of EADL impact for persons who have a degenerative neuromuscular condition (13).

Procedures

An experienced OT, who did not provide services to any participants, interviewed all participants. She was aware of the general purpose of the study, but not of the specific study objectives. The 3 questionnaires would have little to no susceptibility to interpretation or bias on the part of the interviewer as they use forced choice questions or ratings on scales by respondents. Most of the interviews were conducted in-person with participants in their homes. Four interviews were conducted by phone. All interviews followed the same order and most were completed in one session. When completing the PIADS the nonusers were asked to rate how they believed the EADL would impact upon them, should they obtain electronic aids, whereas, the users were asked to rate how the EADL currently impacted upon them.

Data Analysis

The data were first submitted to descriptive analyses. The inferential statistics used to compare the user and nonuser groups included the Fisher's exact test and the Likelihood ratio for analysis of the demographic data; the Mann-Whitney test for non-parametric samples to compare LOMEC and SMAF scores (25); and the t-test for analysis of the PIADS scores.

Results

Statistical analyses of the demographic data shown in Table 1 demonstrated that the two groups were comparable (no significant differences) in terms of age, gender, level of injury, level of education and employment status. However, twice as many users lived alone in apartments or houses with scheduled attendant care, compared with the nonuser group. Two of the users were in apartments with family living within the same building. Whereas more than twice as many nonusers lived with family members, including parents or spouse (56%), compared with 25% of the user group. Both groups estimated that they received a comparable number of hours of attendant-care daily (mean of 6 -7 hours). Those participants living with family noted that their spouse or parent provided an additional 2-4 hours of care per day.

Table 2: Functional Autonomy Measuring System (SMAF) scores: Mean total and domain scores for users and nonusers, and comparison of groups using the Mann-Whitney U test

	EADL Users Mean (SD) *(n=16)*	**Nonusers Mean (SD)** *(n=16)*	**Mann-Whitney U score**	**p value**
SMAF Total	-48.03 (5.3)	-51.06 (3.4)	83.0	NS
SMAF Subscales:				
ADL (maximum score = -21)	-17.69 (2.7)	-18.38 (1.6)	115.0	NS
Mobility (maximum score = -18)	-14.94 (1.5)	-14.94 (1.4)	123.5	NS
Communication (maximum score = -9)	-0.06 (.25)	-0.19 (0.4)	112	NS
Mental (maximum score = -15)	-0.13 (.34)	-0.06 (.25)	120.0	NS
Instrumental ADL (maximum score = -24)	-15.19* (2.7)	-17.50* (2.2)	66.5	.02*

Legend: SD = standard deviation NS = not significant
* = p value ≤ .05

The mean SMAF scores, reported in Table 2, demonstrated that all participants were nearly completely dependent in the ADL and mobility domains, and independent with their mental and communication abilities. The comparison between the users and nonusers on total SMAF scores and on four subscores (ADL, mobility, communication and mental functions) were not statistically significant. This demonstrates that the two groups were of a similar functional status. However, a significant difference was identified for the instrumental activities of daily living (IADL) subscores ($p = 0.02$) indicating that the EADL user group was more functionally autonomous in IADL than the nonuser group.

The findings from the comparison of groups using the Mann Whitney U test demonstrated that EADL users had greater functional abilities for 75% of the 12 LOMEC tasks compared with nonusers, at a statistically significant level of $p \leq .05$ (Table 3). The difference in functional ability was greatest in the domain of leisure/work, where most of the users were functionally independent doing those tasks with the help of their EADL, and the nonusers, by comparison, were largely dependent for help from caregivers to do those tasks. EADL users were much more independent than their nonuser peers with identifying callers at their door and controlling the entry of visitors, corresponding in writing, controlling lighting in their home and positioning themselves for comfort. By comparison, nonusers rated that they could not do those tasks without assistance.

The EADL users were asked to rate the acceptability and availability of their EADL. Most (87.5%) found their EADL fully acceptable because of the benefits that these technologies provided, and reported that their EADL was available to them throughout the day. Only 20% could not operate their system from their bed. All users reported that they had no major problems with the reliability of their systems, and that it was available for them to use daily. The mean scores on the PIADS three subscales are shown in Table 4. There were no significant differences between both groups for each of the subscales, which demonstrates that both groups of participants felt that the anticipated and the real psychosocial impact of EADL was a moderately positive increase in one's competency, adaptability and self-esteem.

Discussion

This study appears to be the most comprehensive evaluation of the impact of EADL to date. This is the first study that has used inferential statistics to compare the experiences of EADL users with nonusers. Our key findings demonstrate that functional abilities within the home were significantly greater when EADL were used and the psychosocial impact of using electronic aids was positive. The 16 EADL users reported significantly greater abilities with 75% of the LOMEC tasks than a comparable group of 16 nonusers.

Results from our study are supportive of findings from earlier studies in which EADL users reported that the technology increases their independence (3, 7, 11). Previous studies

Table 3: The Mean scores on the Lincoln Outcome Measure for Environmental Controls and Audit of Installation Quality (LOMEC)[19] for users and nonusers, and comparison of groups using the Mann-Whitney U test

LOMEC: Domains	Functional Task Items	EADL Users Mean (SD)	Nonusers Mean (SD)	Mann-Whitney U Score	p value
Home Security	Identify callers and control admission	1.13 (.72)	0.44 (.51)	62.5	p=.007**
	Summon help	1.44 (.51)	0.94 (.68)	78.0	p=.034*
	Leaving or re-entering home	1.44 (.73)	0.94 (.93)	89.5	NS
Communication	Operate the phone	1.56 (.51)	1.25 (.68)	97.0	NS
	Converse using the phone	2.00 (.00)	1.69 (.60)	96.0	p=.036*
	Correspond in writing	2.00 (.00)	1.25 (.93)	72.0	p=.003**
Comfort	Ability to position self	1.19 (.54)	0.81 (.40)	86.0	p=.037*
	Control lighting	1.63 (.50)	0.44 (.51)	21.0	p=.00**
	Control heating and AC	0.56 (.89)	0.19 (.54)	102.5	NS
Occupation	Control AV equipment	1.69 (.48)	0.75 (.70)	38.5	p=.00**
	Hobby or recreation activity	1.81 (.40)	0.94 (.85)	55.0	p=.002**
	Voluntary or paid work at home	1.88 (.50)	1.00 (.89)	58.0	p=.002**

Legend: SD = standard deviation NS = not significant
* = p value ≤ .05 ** = p value ≤ .01

asked EADL users to rate the usefulness of their system for various tasks (3, 9-11), while the current study further explored the idea of usefulness. We asked users and nonusers to rate their level of independence with the LOMEC tasks to understand more fully the impact of EADL on independence.

For example, our LOMEC results were more positive and provided greater detail about the impact of EADL on functional abilities than those reported by Harmer & Bakheit's (7) study of 16 EADL users. They modified the LOMEC to ask participants to rate the effects of EADL on their functional abilities with each of the tasks, using a 3-point scale ranging from 'worsening function' to 'improving function'. Their study shows that users felt that their function was improved for only 45% of the tasks. However, their sample differed from ours and the LOMEC scale we used measured level of ability impacted by EADL. Over 80% of their participants had neurodegenerative diseases, such as multiple sclerosis, and their mean age was about a decade older than our group. Participants in their study likely had deteriorating functional abilities due to the progression of their diseases, which may have influenced how they rated their function on that version of the LOMEC. We not only found that EADL users rated their abilities as significantly greater than the nonusers, we also found that the technology enabled over 80% of the users to be completely independent for the communication and leisure/work tasks on the LOMEC. These findings may explain why twice as many EADL users than nonusers were able to live alone, and with less dependence on family members. With this evidence of the positive impact of EADL on function, it is easy to see how Cowan and Turner-Smith (12) found that EADL were used daily by 94% of the 83 users.

Table 4: Mean subscale scores for the Psychosocial Impact of Assistive Devices Scale (PIADS)

PIADS subscales:	**Users Mean (SD)** *(n=16)*	**Nonusers Mean (SD)** *(n=16)*
Competence	2.02 (.77)	1.99 (.66)
Adaptability	1.66 (.86)	1.64 (.79)
Self-Esteem	2.03 (.64)	1.89 (.69)

Legend: SD = standard deviation

All participants in this study were almost completely dependent with self-care and mobility as demonstrated by their similar level of functional disability on the SMAF (17). EADL were not expected to, and did not foster independence in ADL and mobility. On the other hand, EADL would be expected to, and did support significantly greater independence in the IADL domain of the SMAF for the EADL users compared with the nonusers. The EADL functions of electronic door openers, hands-free phone access, and access to the computer enabled users in this study to gain greater independence in telephone and computer usage and in getting out of their home to engage in activities such as shopping.

The PIADS scores for the users demonstrate that EADL devices have a positive impact on their perceptions of competency, adaptability, and self-esteem. Interestingly, the nonuser group had expectations for the psychosocial impact of EADL on their quality of life that were nearly the same as the real impact on the user group. These findings closely match those of our earlier study with persons with neuromuscular conditions (13). In that study the scores for anticipated psychosocial impact of EADL, given by the group of 21 nonusers, were almost identical to those given by the group of 20 users. They also agreed that the impact was more positive for competence and self-esteem, than for adaptability.

What was illuminated in these two studies, and what previous studies have not addressed (3, 7) is the positive opinion that nonusers have about EADL. The PIADS scores imply that nonusers have very accurate knowledge of what EADL could do for them in their daily lives. This leads to the speculation that nonusers would likely choose to obtain an EADL if they were made available to them.

In many communities, EADL is not widely available due to funding barriers (2, 4, 26). The positive findings from this project about the functional and psychosocial benefits of EADL can provide important evidence to make the case to potential third party payers to increase the funding for this technology.

Study Limitations:

This study used a small sample of persons with cervical SCI living in Ontario, Canada, and consequently, the magnitude of differences between groups may be small and generalizing results should be done with caution. Nonetheless, more than 90% of all identified EADL users with SCIs in the 2 urban communities of southern Ontario, Canada agreed to participate in this study. Convenience sampling was used for recruitment of nonusers. In order to increase the sample size, we would recommend enlarging the geographical region for sampling.

There were limitations in two of the measures used for this study. The LOMEC did not have established psychometric properties; however, we tested the measurement properties of a modified version of the scale renamed the MCEADL, and found it to have good validity and reliability (20).

The PIADS appears to be suitable for measuring the psychosocial impact of EADL. We used this tool in another study and found that the EADL users perceptions of the positive impact of EADL on functional independence is consistent with views expressed by users in that study (13). The PIADS fulfills its intended purpose to evaluate the impact of EADL on the user’s perceptions of their psychosocial wellbeing as this influences their quality of life. However, it has limited utility for comparing the quality of life of EADL users with nonusers. In this study we have not formally evaluated the quality of life of the nonusers, and are therefore not able to state whether or not quality of life was improved by provision of EADL.

Conclusions and Recommendations

This study demonstrates the benefits of EADL usage by comparing functional abilities of EADL users with nonusers. Persons with severe physical disabilities due to high level spinal cord injury and quadriplegia have greater functional abilities to engage in a variety of daily tasks when EADL are used. Those who did not use EADL were more dependent upon others in their daily lives. EADL positively influenced user's psychosocial health and perceptions of quality of life.

Although our study provides stronger research evidence of the beneficial effect of EADL than earlier studies, we suggest that consumers and their advocates present our findings with the results of other studies when seeking funding support from third party payers. We suggest that future research focus on estimating the direct and indirect costs associated with EADL and studying the consequences, in terms of psychosocial health and quality of life, of not making these technologies available to those who could benefit from them. Outcomes from these investigations may provide consumers, advocates and lobbyists with important additional evidence that they need to effect change at a policy level.

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Figure 1: Description of outcome items on the Lincoln Outcome Measures for Environmental Controls & Audit of Installation Quality (LOMEC)

Section I: Functional domains within home environment	
Home Security	• ability to identify callers at the door and control admission • ability to summon help • ability to leave and/or re-enter the home
Communication	• ability to operate the telephone • ability to converse using the telephone • ability to correspond in writing
Comfort	• satisfaction with control of the position of beds and chairs • satisfaction with control of lighting • satisfaction with control of heating and ventilation
Leisure/work	• ability to access audio-visual entertainment services • ability to pursue a hobby or recreational activity • ability to undertake work at home
Section II: Acceptability and Availability of EADL system	
Acceptability	• respondent finds the system aesthetically pleasing • installation of system does not damage decoration to home • system does not interfere with the use of other home devices
Availability	• system is fully usable at the end of installation period • system is available throughout the day • system provides reliable operation

Figure 2: Sample Items from the Lincoln Outcome Measures for Environmental Controls & Audit of Installation Quality (LOMEC)

Indicator	**Measures**	**Score**	**Comments**
Home Security: *The respondent will be secure within his/her home*			
The respondent will not be impeded in leaving or re-entering the home	2 = the respondent's need to open and close doors to move within and leave / re-enter the premises have been met 1 = the respondent has some control of doors but feels that mobility is still unnecessarily restricted 0 = the respondent is without any effective control of door opening and closing and feels that this severely restricts mobility.		
Occupation: *The respondent will have recreational or productive occupation at home*			
The respondent is able to access audio/visual entertainment services	2 = The respondent's needs to operate TV, video and stereo equipment have been satisfactorily met. 1 = The respondent's needs to operate television, video and stereo equipment have been only partly met and lack of access to some services (e.g. TV) causes irritation. 0 = the respondent has very limited or no control of audio/visual equipment and is frustrated by this.		

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6

Chapter

Development of the Measure of Control using Electronic Aids to Daily Living

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Abstract

Electronic aids to daily living (EADL) are also known as environmental control systems (ECSs) or environmental control units (ECUs). Descriptive studies have been conducted regarding the benefit of EADL devices. These studies mostly focus on usage, qualify of life and satisfaction. There is a need for the study of functional benefits from EADL usage. This paper reports the development of Measure of Control using Electronic Aids to Daily Living (MCEADL), a tool that measures the functional changes specifically related to the use of EADL. We tested the psychometric qualities of MCEADL with 36 individuals (15 users and 21 non-users of EADL) with spinal cord injuries at or above C5/6 level. MCEADL was administered to the two groups twice, at a time interval of 4-8 weeks. The results of the study indicated that MCEADL has good internal consistency and good to very good test-retest reliability. In this paper, we discuss the possible applications of MCEADL as a clinical outcome measure or a program evaluation tool. Development of an outcome measure tool is an on-going process. Future research is necessary to examine the clinical utility of the measure with different diagnostic groups.

Keywords

EADL, ECU, ECS, outcome measure, reliability

Introduction

Electronic aids to daily living (EADL) can be defined as devices that are used to access, operate, and control electrical appliances for comfort, communication, leisure, and personal security [1]. EADL are also known as environmental control systems (ECSs) or environmental control units (ECUs). EADL allow persons with a severe physical disability such as spinal cord injury to control a wide variety of household and workplace appliances, so that they can be independent of assistance from family members or other caregivers. The history of the EADL dates back to the 1960's when the preliminary systems were designed in England for persons with high-level quadriplegia and poliomyelitis [2]. With the advance of technology, users can now use their EADL devices with a variety of control methods such as single switch, touch screen or voice. Studies of EADL utilization demonstrate that EADL devices are frequently used to operate the phone, TV, stereo, fan and lights [3-5].

The majority of the research that examines the benefits of EADL devices has been descriptive. Symington and associates (1986) interviewed 15 individuals with severe disabilities who reside in institutions and found that EADL helped these individuals achieve and maintain an increase in independence [4]. They were less dependent on the nursing staff for assistance than before they were using EADL devices.

Using an interview tool, Efthimiou, Gordon, Sell and Stratford (1981) compared the activity patterns between 7 EADL users and 13 non-users who had high-level quadriplegia[6]. They found that users of EADL participated more frequently in educational activities, traveling and telephone communication than nonusers. Users also maintained a higher degree of independent functioning than the non-users.

McDonald, Boyle and Schumann (1989) conducted a study on the effect of EADL using a questionnaire with 29 individuals with high-level spinal cord injuries [7]. They found that communication, security and recreation were perceived as the most important benefits of EADL, with telephone, television and room lights being the most important functions. Participants also reported being more comfortable for longer period of time without attendant care when they had access to their EADL.

von Maltzahn et al. (1995) followed 5 individuals with spinal cord injuries who used EADL devices and found that they enjoyed increased independence, security, privacy and comfort [5]. Harmer and Bakheit (1999) reported that EADL users increased their independence, their feelings of self-worth and happiness and their control over the environment, especially in terms of security [8].

Researchers studying the utilization of assistive devices reported that about one third of the devices were abandoned by users [9-11]. In contrast to these reports, Cowan and Turner-Smith (1999) found that 94% of EADL users continue to use their EADL devices daily [12]. Despite the growing body of evidence about the benefits of EADL and the acceptance of the technology by the users, this technology is not widely used by the persons for whom they were designed largely due to funding barriers [13,14].

Background

Assistive technology providers have become increasingly more aware of the need to measure the outcomes of assistive technology intervention [15,16]. Outcomes research that supports the effectiveness and continued use of EADL could help to justify the costs of this technology and influence policy regarding funding [17,18]. DeRuyter (1995) describes five dimensions of outcome measurement: (1) clinical results, (2) functional status, (3) quality of life, (4) satisfaction, and (5) cost [15].

Research that has been conducted regarding the benefit of EADL devices has been largely descriptive of the experiences of EADL users and focuses on use, qualify of life and satisfaction. Few studies have addressed functional outcomes following provision of EADL devices, and those studies had problems with the measures of function that were used [8].

Merbitz (1996) argued that documenting functional changes is important for at least three reasons [19] First, there is a need to demonstrate that the devices are effectively improving client performance. Second, since rehabilitation consumes scarce financial resources, it is important to be cost-effective. Finally, inherent to improving human performance, evaluative information should contain hard data on both process and outcome. To achieve these goals, Merbitz felt that the measurement tool should collect data for demonstration of accountability and as feedback for continuous improvement. Such a measurement system would function as feedback to both client and therapist to keep the therapy on track and promote the most effective use of resources.

Many researchers have stressed the importance in addressing the outcomes of assistive technology from the users' perspectives [20,21]. This trend is consistent with the larger health system context, where there is an increasing emphasis on the consumer's viewpoint on health outcomes rather than the professional viewpoint [22]. Over the years, a number of user-based outcome measure tools have been adapted or developed for use with assistive technologies such as Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST)[23], Psychosocial Impact of Assistive Devices Scale (PIADS)[24], Efficiency of Assistive Technology and Services 6 dimensions (EATS 6-D)[25] and Canadian Occupational Performance Measure (COPM)[26]. However, only the EATS 6-D and COPM assess the functional changes effected by assistive technology devices.

Two important problems with the EATS 6-D tool have prevented us from adopting it for cost utility analysis of EADL. First, it is not available in the English language. Secondly, the tool is administered with assistive technology users before and after provision of the technology. This approach would be appropriate for evaluation of commonly prescribed assistive technologies such as manual wheelchairs, but would have limited feasibility for the study of EADL. EADL are seldom prescribed due to limited funding options, consequently it would take a long time to recruit an adequate sample of new EADL users for a prospective study.

The COPM addresses functional outcomes from the user's perspective. Users are asked to identify the areas of concern and to rate their performance and satisfaction of performance in those areas on a 10-point scale. However, the COPM is a generic tool instead of a specific tool designed to measure assistive technology outcome, and the interviewer must be skilled in capturing functional performance issues specific to the use of EADL devices.

The literature review confirmed the need for an outcome measure of functional abilities related to the use of EADL devices. This paper reports the development and the psychometric quality of Measure of Control using Electronic Aids to Daily Living (MCEADL) [27], a tool that measures the functional changes specifically related to the use of EADL. This paper also describes the methodology used to develop the MCEADL instrument, introduces the general characteristics of the tool and discusses the possible applications of MCEADL as an outcome measurement tool for clinicians providing EADL.

Development of MCEADL

The MCEADL [27] was modified from the Lincoln Outcome Measures for Environmental Controls and Audit of Installation Quality (LOMEC) which was originally developed to evaluate the functional outcomes of environmental control services provided in northern United Kingdom [28]. The LOMEC is an evaluative measure of functional abilities specific to the functions enabled by EADL. It has four functional domains: home security, communication, comfort and occupation, and 3 indicators per domains (12 functional indicators in total). It also includes the quality standards of acceptability and availability, which would allow EADL users to rate their opinions about their system and the installation of their system. It uses three-point ordinal rating scales, which were created specifically for each indicator. Respondents are asked to rate how well they are able to achieve each functional indicator using their EADL. The LOMEC was modified slightly and used by Harmer and Bakheit in their study of 16 EADL users [8]. They added items related to the equipment that had been prescribed to participants in their study, and to measure the frequency and duration of equipment use. They also adjusted the scale to provide a uniform 3-point rating of whether the respondent's functional needs were being met when using the EADL.

We used the original LOMEC in an earlier study in which we compared the functional abilities of 16 EADL users with 16 nonusers, all of whom had cervical spinal cord injuries [29]. The EADL users reported significantly better scores on nine of the 12 functional indicators. EADL appeared to make the greatest impact on occupation (e.g. leisure and work pursuits). In the different study we used the LOMEC for a pre-post evaluation with eight new EADL users [30]. The findings were similar to those in the comparison analysis, which demonstrates that the LOMEC is able to detect differences in functional abilities between users and nonusers and for users before and after provision of EADL. Ratings made by the nonusers and the new users prior to prescription of the EADL were very similar, as were the ratings of the users with the new users after their system was installed.

We identified the following problems when we used the LOMEC. First, the ratings that were created for each scale varied considerably within and across the functional indicators. For example, indicators within the domain of communication measured the respondent's abilities, the indicators within the domain of comfort measured the respondent's satisfaction and several indicators measured whether or not the respondent's needs had been met. Some scales combined more than one aspect of measurement such as measures of ability, satisfaction, and whether functional needs had been met, as shown in Figure 1. Colloquial language, or complex expressions were also included with a few items as shown in Figure 2. These required some explanation by the interviewer. Secondly, the LOMEC was also developed to address the functions provided by EADL commonly used in the UK. There were a few areas missing with respect to functions commonly provided by EADL in North America. Lastly, the 3-point scale was not found to be very sensitive to subtle changes in functional abilities or with satisfaction. Some respondents had difficulty choosing between numbers on some of the scales, as the explanation for both numbers did not apply very closely to their specific situation. Streiner and Norman (1985) point out that the reliability of a rating scale drops as fewer points are used. However, the loss of reliability becomes quite small when there are 7 or more points on the scale. They also provide evidence that demonstrates that people are unable to discriminate much beyond seven points [31].

The content of the LOMEC provides a comprehensive foundation for assessing functional outcomes after the provision of EADL. The following steps were taken to improve this measure and content validity by expanding the content areas and enhancing the measurement abilities of the scales. Content experts, including consumers, service providers, and representatives from industry and funding agencies were consulted through semi-structured interviews and focus groups to obtain their opinions about what to include in an outcome measure for EADL services. Based on their input and experiences in our earlier study we made substantial changes to the outcome measure. We divided the measure into 3 parts and added new categories and items. Four measurement scales were added which changed the measurement capability of this tool substantially. The revised measure is described in greater detail in the next section of this paper. We discussed our proposed changes with the author [32]. He was supportive of these changes which enhance the LOMEC's clarity, clinical utility and potential to detect clinically important and statistically significant change in functional abilities and user satisfaction following provision of an EADL.

Figure 1: Example of LOMEC item in which the scale combines measure of ability and satisfaction

Indicator	Scale	Score
The user is able to pursue a hobby or recreational activity	2 = The user pursues one or more hobbies in a sufficiently independent manner to gain satisfaction or the user has no interest in pursuing a hobby 1 = The user can engage in a hobby only to a limited extent or with assistance and feels that more satisfaction could be gained if he/she had better means of control (state of what) 0 = The user has no means of independently engaging in a hobby and is frustrated by this.	

Figure 2: Example of LOMEC item in which the scale uses colloquial and complex expression of ideas

Indicator	Scale	Score
The user is able to access audio/visual entertainment services	2 = The user's needs to operate television, teletext, video and hifi equipment have been satisfactorily met 1 = The user's needs to operate television, teletext, video, and hifi equipment have been only partly met and lack of access to some services (e.g., teletext) causes irritation 0 = the user has very limited or no control of audio/visual equipment and is very frustrated by this.	

Description of MCEADL

MCEADL [27] is divided into three parts and samples of items from each part are shown in the appendix. Part A records the use and control of the EADL. Respondents are asked to identify the appliances that they use in their home, indicate if the appliances are controlled by the EADL or by commercial remote controls. Respondents also report on where, how and if there have been any changes in their use of their EADL. Part B concerns the functional impact of EADL and includes 26 tasks/functions. These 26 items are grouped under 4 functional domains: home security, comfort, communication, and occupation.

There are four 7-point scales for rating: 1) importance; 2) ease of performing tasks from chair; 3) ease of performing tasks from bed; and 4) satisfaction with performance for each task/function. Part C includes items for rating perception of EADL devices and services. These are grouped under three domains: acceptability, availability and device. Respondents rate how true the statement is to their situation and the importance of these items on 7-point scales. The MCEADL can be used with both users and non-users of EADL, or as an outcome measure for users before and after provision of EADL to compare functional performance and satisfaction with performance.

Methods

Design

A comparative study between EADL users and non-users was conducted to evaluate the ability of MCEADL to detect the differences in functional status between the two groups. A comparative study methodology was chosen instead of a prospective study because of the anticipated difficulties with recruiting a large enough sample for statistical analysis in a time efficient manner. All participants were interviewed twice at a time interval of 4-8 weeks. Most of the study participants were interviewed in their place of residence, place of work or place of study. Two participants completed both interviews by phone. Three participants completed the second interview by phone. The telephone interviews were chosen for convenience because these participants lived a long distance from the centre in which the study was conducted.

Procedures

The interviewers were two occupational therapists with good interviewing skills, and familiarity with EADL and the study. They were not service providers to any participants. The initial interview with the participants started with the administration of the Functional Independence Measure (FIM) [33], followed by the questions on personal demographics to ensure that all participants met the inclusion criteria for functional abilities and EADL usage. Following that, the MCEADL was administered. In the second interview, participants were asked to respond to all the items on Part B and Part C of the MCEADL. To ensure consistency of scoring, the two interviewers took part in the interviews with eight participants together but scored the questionnaires independently. They took turn asking the questions. Due to the small number of participants that we have inter-rater observations on, we could not do a statistical analysis of inter-rater agreement. An informal comparison of the raters suggested that agreement was good.

Participants

A total of 36 adults with spinal cord injuries or conditions provided informed consent for participation in the study (See Table 1). The participants were recruited through three major rehabilitation centres in Ontario, Canada. All participants had spinal cord injuries at the level of C5/6 or above with the exception of three participants, one with Guillan Barre syndrome, one with transverse myelitis and one with peripheral neuropathy, all presented with a functional level at or above C4/5 level spinal cord injuries. All participants relied on powered-wheelchairs for mobility. The mean age of the participants was 41 years.

Among the participants, 15 were EADL users and 21 were non-EADL users. Persons were included as EADL users if they activated two or more appliances by means of devices that were chosen to facilitate the user's function. Persons were included as non-users if they directly activated most of the appliances using commercial remote controls and were able to use a standard or adapted telephone (e.g., Ameriphone). There was only one female in the user group, and 9 females in the non-user group. All of the participants completed at least Grade 9 education in a high school, with most participants having received or completed university or college education.

Table 1 Participant demographics

		Users	**Non users**	**p value**
AGE	Mean (SD)	41.33 (12.04)	42.62 (14.08)	0.78
GENDER	Male	14	12	0.02*
	Female	1	9	
LEVEL of SCI	C3/4 and above	5	4	0.07
	C4/5	7	5	
	C5/6	3	12	
Education	High school	3	3	0.68
	College or university	12	18	
FIM	Mean (SD)	54.80 (0.23)	57.048 (0.24)	0.34

* statistically significant ≤ 0.05

Data analysis

Prior to analyzing the MCEADL data, statistical analyses were performed to demonstrate that the two groups being compared were similar in terms of age, gender, level of injury, education and FIM scores. Student's t-tests were used to compare the means of the age and FIM scores of the two groups. Fisher's exact tests were used to examine the relationship between group membership in terms of education and gender. Likelihood ratio was used to examine the relationship between level of injuries and group membership.

In examining the MCEADL results, data from each part of MCEADL was analyzed separately. Descriptive analysis was completed on data from Part A, B and C of the MCEADL. Cronbach's Alpha was used to establish the internal consistency of the items in the MCEADL. The intraclass correlation coefficient (ICC) was used to evaluate test-retest reliability of the tool. The mean total composite MCEADL scores for importance, satisfaction and ease of doing activities from bed and wheelchair were also calculated. Scores for each of the functional domains were compared to evaluate possible differences in the impact of EADL devices in the different functional domains. As internal consistency and test-retest reliability were evident, t-tests were then used to compare the mean total scores and the mean scores for each of the four functional domains between users and non-users. A comparison on ease of performing tasks in bed and in the wheelchair between the users and the non-users was done using a paired t-test. In Part C, Cronbach's alpha and Pearson correlation coefficients were calculated to demonstrate the psychometric quality.

Results

The two groups did not differ in their mean age (t=0.286, df=34,p=0.78). There was a significant relationship between gender and group membership. Women were less likely to be users than men (Fisher's exact test p=0.02). There was no significant relationship between level of injuries and group membership (Likelihood ratio=5.22, df=2,p=0.07). Group membership was not related to whether or not they had attended college (Fisher's exact test p=0.68). The two groups did not differ in their mean FIM scores (t=0.96, df=34, p=0.34) (See Table 1 for descriptive statistics).

Part A – Use and Control

Non-users accessed a mean of 7 electrical appliances by direct access (e.g., mouthstick, a pointer inserted in a universal cuff, or a finger) or with standard remote controls. EADL users accessed a mean of 12 electrical appliances through EADL devices and standard remote controls. All users were using their EADL devices.

Table 2 Measurement Qualities: MCEADL (Part B)

	Cronbach's Alpha	ICC - test-retest reliability (p value)
Total MCEADL	.92	0.89 (<.001)
Home security	.85	0.78 (<.001)
Communication	.87	0.89 (<.001)
Comfort	.73	0.78 (<.001)
Occupation	.95	0.83 (<.001)
Importance	.87	0.75 (<.001)
Ease from chair	.90	0.90 (<.001)
Ease from bed	.92	0.85 (<.001)
Satisfaction	.84	0.81 (<.001)

Part B – Functional Impact of EADL.

The measurement properties of MCEADL, Part B are presented in Table 2. The Cronbach's alpha for evaluation of internal consistency was higher than 0.73 in all of the analyses. The Intraclass correlation coefficients (ICC) for all calculations were higher than 0.74 (p<.001) for test-retest reliability and were higher than 0.996 (p <.001) for inter-rater reliability.

The comparisons of mean composite MCEADL scores are shown in Table 3. Both users and nonusers rated the importance of functional items on the MCEADL to be equally important in their daily lives. There was no statistical difference in importance scores between the 2 groups. Users gave significantly higher mean scores than nonusers for ease of doing tasks from chair and from bed, satisfaction with abilities to do tasks, and with performance in all four functional domains.

Part C – EADL devices and services.

Table 3 presents the psychometric properties of MCEADL in measuring users' perception of EADL devices and services. Cronbach's alpha was higher than 0.55 for the three domains of measures, namely acceptability, availability and device. Test-retest reliability was statistically significant for Acceptability (p<.001) and Devices (p=0.031), but not significant for Availability (p=0.06).

Table 3 Comparison of MCEADL total composite scores and composite functional domain scores between users and non-users.

		Composite mean (SD)	**t**	**df**	**p value**
Total score: Importance	Users (15) Non-users (21)	5.40 (0.92) 5.34 (1.36)	0.13	34	0.90
Total score: Ease from chair	Users (15) Non-users (21)	4.98 (0.95) 3.98 (1.50)	2.46	33.6	<0.05*
Total score: Ease from bed	Users (15) Non-users (21)	3.81 (1.14) 2.06 (1.32)	4.14	34	<0.01**
Total score: Satisfaction	Users (15) Non-users (21)	5.22 (0.70) 4.19 (1.19)	3.01	34	<0.01**
Functional Domains		**Composite score** - ease & satisfaction			
Home security	Users (15) Non-users (21)	5.14 (0.78) 4.28 (1.23)	2.58	33.6	<0.05*
Communication	Users (15) Non-users (21)	5.27 (0.93) 4.46 (1.20)	2.18	34	<0.05*
Comfort	Users (15) Non-users (21)	3.77 (0.83) 2.91 (0.83)	3.08	34	<0.01**
Occupation	Users (15) Non-users (21)	4.93 (1.27) 3.70 (1.23)	2.94	34	<0.01**

* statistically significant ≤ 0.05

** statistically significant ≤ 0.01

Table 4 Psychometric Qualities: Measures of Users' perception of EADL devices and services (Part C)

Part C category	Cronbach's Alpha
Acceptability	.66
Availability	.65
Device	.55

Discussion

Measurement properties of the MCEADL

Part B of the MCEADL demonstrated good internal consistency with Cronbach's alpha coefficients ranging from 0.73 to 0.92 for the overall MCEADL scores, the four functional domains, and the user's perception of importance, ease and satisfaction, as these scores fall within the range recommended by Nunnally and Bernstein [34]. This high level of internal consistency demonstrates that the items within Part B as a whole and in the functional domains are measuring the same constructs, which also supports the content validity of this tool [31]. Not surprisingly, both the users and nonusers rated all functional items in Part 2 as equally important within their daily life at home. This finding supports the content validity of the tool, and suggests that the functional tasks in the categories of home security communication, comfort, and occupation are very relevant to persons with severe physical disability.

In Part C of the MCEADL the items included in the domains of Acceptability and Availability appeared to be measuring various aspects of those constructs, as the Cronbach's alpha scores were slightly below .70, at .66 and .65 respectively. The four items within the Device domain were measuring several different things about the device including opinions about ease of use, training, and device costs. It is therefore understandable that the Cronbach's alpha coefficient was considerably lower at .55. In view of this, and also recognizing that device effectiveness is well addressed in Part B of the tool, we have decided to revise this domain and will focus on service issues here.

This study provides strong support for test re-test reliability of the MCEADL. The ICC's were in the range of 0.74 to 0.90 for Part B with a very high statistical significance ($p<.001$). With regards to Part C, except for the Device domain, the Pearson correlation calculation also demonstrated that the test-retest reliability for Acceptability and Availability was statistically significant. It is unclear why the test-retest reliability was low for the Device category. However, because most of the participants have had their EADL for more than 2 years, it is possible that they had difficulty remembering any issues concerning the funding and installation of their EADL devices.

It was not necessary, nor appropriate to assess the psychometric properties for the descriptive information collected in Part A of the MCEADL. However, the study results show that this part of MCEADL would be a useful clinical tool to document clients' needs for EADL devices and their preferred access method. The latter part of Part A addresses the use of EADL devices, which is a very useful element in any outcome measure for program evaluation of assistive technology as it demonstrates accountability. Information that can be gathered with this part of the tool includes usage, change in usage and frequency of use.

Comparisons of MCEADL scores between EADL users and nonusers

The MCEADL is intended to be an outcome measure to evaluate the functional impact of EADL. Thus, it is critical that this tool should detect change or differences in functional performance. In this study, the MCEADL did detect clinically significant and clinically important differences in functional performance and in satisfaction with performance between users and non-users. Thus we feel optimistic that this tool could detect changes in client's functional performance pre and post provision of EADL devices on an individual basis or at the program level. Further research is required to examine the responsiveness of this tool to change over time.

The EADL users reported significantly greater ease in doing the tasks listed in the MCEADL Part B, than the non-users. They also rated greater satisfaction with their ability to do the MCEADL tasks. The EADL users accessed nearly twice as many electronic devices within their homes as nonusers (users accessed a mean of 11 devices; nonusers accessed a mean of 7 devices), and found it significantly easier to do tasks with their integrated EADL system, rather than relying, as the nonusers did, on remote controls and manual efforts to operate electronic devices around their homes. The most significant difference in ease of performance can be seen in users' ability to control appliances from their bed. Having the ability to do tasks while in bed is important for persons with tetraplegia, particularly those living in attendant care environments, as it is very common to be put in bed soon after dinnertime, when their attendants leave.

These findings support those from our earlier study with the LOMEC, in which EADL users rated significantly greater abilities with 75% of the LOMEC tasks than the nonuser group [29]. While our MCEADL results demonstrated that EADL users had greater ease and greater satisfaction with their performance of tasks for home security, comfort, communication and occupation, these findings should be interpreted with caution because the objective of the study was to establish the measurement properties of the MCEADL. However, these findings add to the growing body of knowledge about the functional benefits of EADL [2,4,6-8].

Clinical Application of the MCEADL

The MCEADL Part B consists of 26 items and participants are asked to rate importance, ease from chair, ease from bed and satisfaction with each of the items. While it is possible to compare individual data between pre and post measures, it would be a daunting task to draw clinically relevant conclusions from 104 sets of ratings. For clinical applications we recommend that the MCEADL data be grouped in the following ways: the total functional impact of EADL, the respondent's rating of importance, ease and satisfaction with functional performance, and the scores in 4 functional domains (home security, comfort, communication, and occupation). In this way the total MCEADL score can be used as an overall indicator of changes in clients' functional control of electrical appliances.

By focusing on the user's perspective, the MCEADL can be used to evaluate individual client's needs, ease of control before and after using EADL devices and satisfaction with their functional abilities to control electronic appliances. The data gathered from the four functional domains in Part B could help clinicians focus their EADL intervention with clients to a specific functional area. A pre and post evaluation may provide information on the functional area that may require further intervention. However, it would be important to conduct further research to evaluate the utility of the MCEADL in clinical settings.

Limitations and Recommendations

This study was conducted with 36 individuals (15 users and 21 non-users) with spinal cord injuries. We made all reasonable attempts to contact all EADL users with spinal cord injuries who met the inclusion criteria in the area serviced by the three organizations involved in this study, but the maximum number of users we could recruit was 15. While the sample size was adequate for statistical analysis, it was somewhat small and should be noted as a limitation.

The selection criterion for a minimum education of Grade 9 was both a strength and a limitation. The minimum education level ensure that participants could understand the questions and the rating scales used in the interview, but it limited the representation of the participants of this study to the entire spinal cord injuries population. As this study was conducted only with individuals with spinal cord injuries, the application of the results should be limited to this population. Future research is necessary to test the application of MCEADL for other populations.

Conclusion

This study demonstrated MCEADL is a promising new measure for the evaluation of functional performance and satisfaction with performance using EADL. We demonstrated that the measure has good internal consistency and good to very good test-retest reliability. We also demonstrated that this tool discriminated statistically significant differences in ease of task performance and satisfaction with performance between EADL users and nonusers on MCEADL Part B total score and sub-domain scores. MCEADL appears to be a valid tool that shows promise for measuring outcomes of EADL intervention, especially for measuring subjective experiences of changes in functional abilities effected by the EADL devices. In this study, we tested the measurement properties of the MCEADL with a group whose disabilities (spinal cord injuries), while severe, are relatively stable. Future research is necessary to examine the clinical utility of the measure with different diagnostic groups.

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7

Chapter

Electronic aids to daily living and quality of life for persons with tetraplegia

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Abstract

Objective: To compare the satisfaction with quality of life (QOL) of adults with spinal cord injury (SCI) who use and do not use electronic aids to daily living (EADLs).

Design: cross-sectional study.

Setting: the homes of participants living in large urban communities.

Participants: included 36 persons with spinal cord injuries or conditions at or above C5/6 level, who were living in the community; 15 used electronic aids to daily living (EADL) at home and 21 formed the comparison group of non-users of EADL.

Intervention: participants received no interventions as part of the study.

Main Outcome Measure: Quality of Life Profile-Physical Disabilities (QOLP-PD).

Results: Both groups rated the levels of importance of all aspects of QOL equally. The EADL users rated their satisfaction with QOL significantly higher ($p<.01$) for total QOLP-PD scores and for 4 of the 9 domains, including all 3 domains of belonging. There was no difference between the groups for age, FIM scores, level of education, and hours of paid attendant care. There were more males in the EADL user group and they had higher levels of SCI.

Conclusions: EADLs appear to contribute to the experience of greater subjective QOL for persons with severe physical disability from high SCI. The QOLP-PD was found to be a valid measure of QOL for this population, and because it could discriminate differences in QOL between EADL users and nonusers it may be a useful measurement scale for evaluating the impact of other rehabilitation interventions.

Key Words:

Assistive technology, spinal cord injury, quality of life, activity, participation, electronic aids to daily living

Introduction

The prevalence of spinal cord injury (SCI) worldwide is estimated to be 200 to 750 per million population, and approximately one third have tetraplegia (1). Persons with tetraplegia experience a profound, life-changing disability, and a wide range of activity limitations and participation restrictions resulting from the severity of their impairments (2). A key goal for rehabilitation for persons with tetraplegia is to enable increased autonomy and participation in activities that provide meaning, purpose and enjoyment in their daily lives (3). Factors that contribute to life satisfaction and quality of life (QOL) for persons with spinal cord injury (SCI) include high levels of activity, engagement in productive and leisure activities, social integration, access to the community, and community integration (4-6). Through qualitative studies, persons with SCI have said that having choices and spontaneity in their daily activities, and engaging in activities that are personally meaningful and which contribute to personal development contributes to their well-being and QOL (5, 7, 8).

Electronic aids to daily living (EADLs) - also known as environmental control systems - are assistive technology interventions that are prescribed by rehabilitation professionals to increase autonomy, and in turn to improve QOL. EADLs enable users to independently operate electronic devices such as telephones, door openers, lights, computers and personal entertainment systems through alternative access within their home or workplace (9). EADL users have reported that their EADL system affords them greater functional abilities and independence in their daily life (10-14). Persons with tetraplegia have reported significantly greater ease and satisfaction with using their EADL to do a variety of daily activities for home security, communication, comfort, and for personal development and leisure than comparison groups of nonusers (12, 14). Persons with tetraplegia who do not use EADLs can experience severe limitations in what they do in their daily lives, and are typically dependent upon family, friends or caregivers for help with most daily activities (11-13).

Despite evidence supporting the benefits of EADLs, they are neither widely prescribed nor commonly used by persons with severe physical disabilities (15, 16). This is largely due to a scarcity of funding for this technology. EADLs are not funded by many insurers, government and other third party payers because they are not deemed "medically necessary" (12, 15-17). There is also a lack of awareness about this technology. Authors argue that rehabilitation providers and those who could benefit from this technology should be educated about the potential benefits of EADL, including the impact on QOL (12, 15, 17).

It is clear from the literature on QOL and SCI that participation in daily activities is linked with QOL (4-8). EADLs are prescribed to enable persons with tetraplegia to engage more fully in daily activities, and studies have demonstrated that those who use EADLs have greater ease, control and choice in doing daily activities than nonusers (11, 12, 14). Thus, we hypothesized that people who use EADL will have significantly higher self-reported QOL than those who do not use this technology. While the psychosocial impact of EADLs has been found to be positive (12, 18), the QOL of EADL users has not been compared with a group who do not use this technology. The objective of this study was to compare and examine differences in subjective QOL of EADL users with a group of nonusers.

Methods

Design

A cross-sectional design was used to compare the QOL of a group of EADL users with a group of non-users. Participants were recruited from three large rehabilitation centres in south-central Ontario, Canada. All centers gave ethical approval for the study.

Participants

Persons with tetraplegia from SCI or who had a similar condition at the level of C5-6 or higher, who were living in the community and had FIM scores of 65 or less were considered eligible for this study. We defined EADL users as those who were able to activate more than two appliances in their home, such as a home entertainment system, door opener, computer and security system by means of special electronic access devices. Non-users had no electronic access control methods within their own home other than commercial remote controls and/or non-electronic, direct access methods to control equipment, such as a standard or adapted telephone.

The clinical technology programs (including seating, augmentative and alternative communication, and EADL services) at three rehabilitation centres identified 84 potential participants for the study. Of this group we did not have the correct contact information for 15 persons, 4 were hospitalized, and 29 declined to participate. Thirty-six adults (mean age of 42.1 years; range 17 to 79 years of age) with high spinal cord injuries (C5/6 or above) or conditions (three participants had Guillan Barre syndrome, transverse myelitis or peripheral neuropathy) agreed to participate in this study. All used power wheelchairs for independent mobility within their home and community, and lived in a non-institutional setting. Fifteen participants were EADL users and 21 were non-EADL users. All participants had a minimum of Grade 9 education, with most participants having received or completed university or college degrees. Table 1 describes the sample in detail. Most of the study participants were interviewed in their place of residence, place of work or place of study, while two participants completed interviews by phone.

Measures

The challenge was selecting an appropriate QOL measure for this study. We ruled out most QOL measures because they were not developed with or for persons with SCI, and consequently may not yield relevant nor meaningful results (5, 6, 19). SCI researchers recommend using subjective measures to examine QOL from the individual's perspective (5, 6, 20).

The Psychosocial Impact of Assistive Devices Scale (PIADS) (21) was developed to examine the impact of assistive technology on psychosocial well-being and QOL. In a few studies PIADS findings demonstrated the positive impact of EADL on psychosocial well-being, (12, 13) and also showed that EADL nonusers anticipated the impact of the technology to be the same as users' have rated the impact (12, 18). However, the PIADS was not designed to assess the QOL experiences of persons who are not using technology, thus is not an appropriate measure for estimating the differences in QOL between EADL users and non-users.

The Quality of Life Profile for Physical Disability (QOLP-PD) (18) is a subjective measure developed with input from persons with SCI and focuses on areas of QOL that have the potential to be influenced by using EADLs. This tool shows promise for evaluating the impact of rehabilitation interventions that address activity and participation, thus was chosen for this study.

The Quality of Life Profile: Physical Disabilities (short version) (QOLP-PD) (22).

The QOLP-PD is suitable for people from 16 – 64 years, with a variety of physical disabilities, including high SCI. The QOL Model developed at the Centre for Health Promotion at the University of Toronto provides the theoretical underpinnings for this measure (23). The measure and model acknowledge people's need to express who they are (being), their needs to belong and feel connected (belonging), and to express their individuality by making their own choices and decisions, and pursue their goals and dreams (becoming). The model has also been applied to people with developmental disabilities, adolescents, and the elderly (24-27).

The three main constructs of quality of life - being, belonging and becoming - are further subdivided into 3 sub-domains as shown in Table 2. The measure consists of 72 items, with 54 items scored for importance and satisfaction. Response options range from 1 (not important at all/not at all satisfied) to 5 (extremely important/extremely satisfied). Two additional questions are included in each sub-domain; one concerning the amount of control the respondent feels he or she has over that part of his or her life, and the other about the potential opportunities available to the respondent. Control and opportunities response options range from 1 (the respondent has much more control/opportunities than he or she wants) to 5 (the amount of control/opportunities is much less than the respondent wants), with a middle rating of 3 (the opportunities and control are "just right").

Renwick and colleagues reported on two measurement studies for the QOLP-PD (22). Face validity is high, given that the content for the tool is based on in-depth interviews with adults with physical disabilities, including spinal cord injuries. Specific items were generated by a group of adults with physical disabilities, rehabilitation service providers, and researchers who specialize in quality of life and rehabilitation. The authors also demonstrated that the QOLP-PD has adequate construct and concurrent validity, and sub-domain internal consistencies that had Cronbach's ɑ ranging from .67 to .93.

Demographics Two tools were used to collect demographic data. We developed the Personal Profile Form for this study to gather basic information about level of injury, education and work, living arrangements, amount of attendant care, and how electronic devices were accessed within the home. We also used the Functional Independence Measure (FIM^{TM}) (28) to examine and compare the functional level of the two groups of participants. The FIM is a well-known measure of independence in ADL that uses a 7-point rating scale for 18 items. The validity and reliability is well-established with population samples, including those with high SCI (28-31).

Procedures

One of two occupational therapists (OTs) who had a minimum of 2 years related clinical experience, and who were not service providers to participants, conducted the interviews. The FIM and the questions on personal demographics were administered first to ensure that all participants met the study inclusion criteria.

Data analysis

For our primary analysis we used a paired t-test to compare the mean total QOLP-PD importance and satisfaction scores for the two groups. For a secondary analysis of QOL variables we used independent samples t-tests to study group differences on each of the 9 QOLP-PD domains for importance, satisfaction, and control and opportunities. For these analyses we set the Type 1 error probability at a=.01 (2-sided) to lessen the likelihood of making a Type 1 error. We did not use the Bronferroni procedure as it tends to overcorrect with multiple variables (32). We used the Fisher's Exact Test to compare the two groups on key demographic variables. Descriptive statistics (means, SDs, counts) for both groups were calculated for demographics and ratings of importance, satisfaction, control and opportunities on the QOLP-PD.

Results

Demographics and Functional Status

The two groups did not differ significantly in their mean age, level of education, mean FIM scores, hours of paid attendant care received weekly, nor number of hours spent out of bed daily (see Table 1 for descriptive statistics, and Table 3 for FIM scores). There were significantly more women in the nonuser group than in the user group. Further, the EADL user group had significantly higher levels of tetraplegia with 80% at levels of C4-5 or higher, compared with 43% of non-users. Sixty percent of users and 86% of non-users reported that they receive unpaid assistance from family members and friends each week. Non-users reported 2.5 times as many hours of unpaid assistance (mean of 25.4 hours) than the user group (mean of 10.4 hours).

EADL users had their system for 0.2 –19 years (Mean 6.1 years, SD=5.49), and all reported that they currently used their system. Fourteen users regularly used all available functions on their system, and 6 users said that they would like to do more with their EADLs. Users accessed a mean of 11 (range of 7 –15) electronic appliances through their EADLs, and 3 with standard remote controls. Non-users accessed a mean of 7 (range of 0 – 10) appliances by direct access (e.g., mouth stick or a pointer inserted in a universal cuff) or with standard remote controls. Two nonusers relied fully on human assistance.

Quality of Life Scores

Table 4 presents the mean total scores for the users and non-users and their ratings of importance, and satisfaction in the nine categories of quality of life. There was no significant difference between EADL users and nonusers for total mean QOLP-PD importance ratings. Similarly, we could detect no difference in importance ratings between groups on all the subdomains of quality of life, with all the mean ratings greater than 3. EADL users reported significantly higher total mean ratings of satisfaction with quality of life (p<.01) compared with the nonuser group. The users also reported significantly higher ratings of satisfaction (p<.01) with the following 4 categories: physical being, practical becoming, leisure becoming and growth becoming.

The t-test comparison of mean scores for control and opportunities for both groups across the 9 QOLP-PD subdomains were not significant at p<.01. Both groups reported that they have about the "right" amount of control (mean score of 2.89) and opportunities (mean score of 2.71), with mean domain scores ranging from 2.19, which means just less control and opportunities than desired, to 3.47, which means just more control and opportunities than desired.

Table 1: Participant demographics

		Users (n=15)	Non users (n=21)	p values
Age	Mean (SD)	41.33 (12.04)	42.62 (14.08)	NS
Gender	Male	14	12	<0.05*
	Female	1	9	
Level of SCI	C3/4 and above	5	4	<0.05*
	C4/5	7	5	
	C5/6	3	12	
Education/ Work	High school	3	3	NS
	College or university	12	18	
	Currently attending school	3	4	
	Working – Paid	3	5	NS
	Working – Volunteer	9	12	
Home situation	Lives alone	9	10	NS
	Lives with roommate or family	6	11	
Hours of paid attendant care weekly	Mean (SD)	56.2 (47.06)	54.8 (55.3)	NS
Hours spent out of bed on a typical day	Mean (SD)	12.0 (3.66)	12.5 (2.91)	NS
Hour of unpaid assistance weekly	Mean	10.4	25.4	<0.01**

Legend: NS = not significant at p value >.05
* statistically significant at the 0.05 level
** statistically significant at the 0.01 level

Table 2: QOLP-PD domains, sub-domains and descriptors of sub-domains

Being	Physical Being	*Your body and health*
	Psychological Being	*Your thoughts and feelings*
	Spiritual Being	*Your beliefs, attitudes and values*
Belonging	Physical Belonging	*Where you live*
	Social Belonging	*The people around you*
	Community Belonging	*Access to community living*
Becoming	Practical Becoming	*The practical things you do*
	Leisure Becoming	*The things you do for enjoyment*
	Growth Becoming	*The things you do to improve yourself*

Table 3: Mean FIM functional domain and total scores for both groups

Functional Domain	**Users** mean scores	**Nonusers** mean scores
Self-care	1.33	1.67
Sphincter Control	1.00	1.00
Mobility	1.78	1.17
Locomotion	3.56	3.26
Communication	7.00	7.00
Social Cognition	7.00	7.00
Total Score	**54.80**	**57.05**

Note: t-test comparisons between groups were not significant at p value >.05 for total and functional domain scores.

Table 4: Mean scores for ratings of importance and satisfaction on the Quality of Life Profile – Physical Disabilities.

	Mean Importance Rating (SD)		**Mean Satisfaction Ratings(SD)**		**t-test for satisfaction**
	Users	**Non users**	**Users**	**Non-users**	**p values**
Total Score	**4.15 (.52)**	**4.11(.58)**	**4.03 (.58)**	**3.39 (.65)**	**p=.005***
Physical being	4.55 (.37)	4.20 (.92)	3.72 (.71)	3.03 (.80)	p=.010*
Psychological being	4.45 (.64)	4.40 (.68)	4.14 (.75)	3.59 (.92)	p=.062
Spiritual being	4.15 (.79)	4.52 (.57)	4.15 (.83)	3.56 (.76)	p=.035
Physical belonging	4.64 (.30)	4.50 (.66)	4.41 (.66)	3.79 (.78)	p=.017
Social belonging	3.81 (1.16)	4.08 (.72)	4.15 (.67)	3.71 (.97)	p=.138
Community belonging	4.21 (.58)	4.13 (.82)	3.75 (.70)	3.23 (.92)	p=.073
Practical becoming	3.40 (.81)	3.26 (.88)	3.97 (.73)	3.02 (.99)	p=.004*
Leisure becoming	3.62 (1.02)	3.90 (.91)	3.93 (.68)	2.99 (.64)	p=.001*
Growth becoming	4.43 (.49)	4.20 (.71)	4.11 (.53)	3.47 (.770)	p=.009*

Legend * = statistically significant at the 0.01 level

Discussion

Our results demonstrate that a significantly increased level of satisfaction with QOL for persons with SCI tetraplegia is associated with using EADLs. EADL users rated their level of satisfaction with quality of life significantly better than nonusers on the total QOLP-PD score, and on 4 of 9 domains. The use of EADL is associated with the achievement of greater satisfaction with physical being and with all three domains of becoming.

All participants in this study uniformly rated the elements of quality of life included in the QOLP-PD, as important in their life. In fact, mean ratings were greater than "4" in 6 of 9 categories for users and in 7 of 9 categories for nonusers. This means that those aspects of quality of life were rated as very to extremely important to participants. These findings support the content validity of this measure of quality of life for this population (22, 33, 34). This is encouraging considering that researchers have questioned the application of many commonly used QOL measures for people with SCI. Many tools are not developed for this population, and their content is not considered relevant nor important to persons with SCI (5, 6, 20).

It is not surprising that the user group rated that they were very satisfied on all three categories of becoming. This domain and its sub-domains focus on the things people do to fulfill their hopes and goals and is about the practical things people do each day, the things people do for enjoyment, and the things people do to improve themselves. These findings may be explained in part by the enabling impact this technology has on communication (e.g., using phones, email and internet for social, vocational, educational and leisure activities), comfort (e.g., operating lights, window coverings, AC/heating), and on leisure activities (e.g., using personal entertainment systems to watch TV, DVD's and to listen to music, or using door opener to leave and enter home to go out for various activities) (14).

The dimensions of QOL that were rated higher by EADL users may be influenced by the ease with which EADL users can do various activities from both their bed and wheelchair, the volitional control allowed by EADL, and the privacy enabled when they rely less on caregivers for help as reported in our earlier work (12, 14). While the non-users could also access many electronic appliances, they had more difficulty and were less satisfied doing activities using remote controls and manual methods (35). In other studies, users reported that EADLs enabled them to feel competent and able to adapt in order to do various daily activities that are activated and controlled by their device (12, 13, 18) . Our results are also consistent with what others have found contributes to QOL and well-being for persons with SCI, including being active in one's daily life, having choices, being spontaneous, and doing things that have personal meaning and purpose (5, 6, 8).

Both the EADL users and the nonusers agreed that they have about the right amount of control and opportunities in their lives. Using EADLs did not seem to be linked with these aspects of QOL. This finding was surprising considering that this technology allows users the opportunity to operate multiple electronic devices when they want to or need to in their daily life (12, 13). However, the demographic variables for both groups in relation to education, employment, living arrangements and amount of attendant care were comparable. This may account for some of the similarities in these aspects of QOL, as vocational status, and living in the community are associated with life satisfaction and QOL (4, 5).

Both groups had comparable functional levels on the FIM total score (mean FIM scores of 55 for user group and 57 for the nonuser group) and all the FIM functional domains. These levels indicate that all participants have severe functional limitations in self-care and mobility, and are dependent on caregivers for most of their daily needs (36). In our study, nonusers reported much greater reliance on friends and family for help with daily tasks than EADL users, indicating that they used 2.5 times more non-paid attendant care per week. This may have negatively impacted on their perception of their QOL. The nonusers may have needed help with many of the tasks that the users were able to do independently using their EADL.

EADL users were more likely to be men. While males are nearly 3 times as likely to have a SCI than females in Ontario (37), we found that only 10% of the females in our study used EADL. This finding led us to speculate that the gender differences between the 2 groups could explain the differences in QOL between the groups. However, when we compared the QOLP-PD scores between the males and females we found no differences. Another possible explanation for the gender differences is that funding opportunities for EADLs may be less accessible to females with SCI than males. Although further research is needed to explore the association of gender and EADL use, it may be because more males than females incur SCI from motor vehicle and work-related accidents (37, 38) ,and most EADL funding comes from automobile and worker’s compensation insurance in Canada (39). Constrained access to such economic resources is associated with diminished QOL for people in general and for those with SCI (40).

Most users reported having their EADLs for more than 2 years. Consistent with the findings of others (41), we found that all EADL users continued to use their devices to full capacity on a daily basis (for a mean of 6 years). This too is an important finding, considering that EADLs can cost $8,000 to $15,000 (17) and dissatisfaction with and abandonment is a problem with other assistive technologies (42, 43). The improved ability to do things for themselves (12, 14) and quality of life afforded by this technology may have influenced the continued use of EADLs. This finding lends support to Lenker & Paquet’s model (44), which proposes that the impact of assistive technology is a predictor of future use of that technology. Some EADL users in our study also reported a desire to expand the capability of their EADL devices. It can be argued that having more functions on their system would further increase their autonomy.

Study Limitations

This study has several limitations. The survey design allowed us to study the association between EADL use and aspects of QOL that participants reported were important. Although we found an association between reported use of EADLs and higher satisfaction with QOL, we are unable to determine the causal direction of this relationship and disentangle the contribution of EADL use from the contribution of other contextual factors.

We recruited a sample of adults with SCI from the three largest rehabilitation centres in Ontario, the most populous province in Canada. We estimate that our sample included about 30% of the EADL users in Ontario with high SCIs. These centres were based in large metropolitan cities. Consequently, our sample may not have been representative of people who live in smaller towns or rural environments. We minimized interviewer bias by having the research OT administer the measures using standardized instructions and respondents used rating scales to indicate their choices.

Conclusions

Our research suggests that persons with SCI tetraplegia who use EADLs experience greater satisfaction with their QOL than those who do not have this technology. Our study contributes to growing evidence that these devices are cost effective, because they make it easier to do a variety of daily activities and are used regularly (11-14, 16). Increased public and private funding for EADLs may be warranted for this population. Our study also shows that the QOLP-PD reflects what matters in the daily lives of tetraplegics. Rehabilitation researchers and service providers may find that this tool is relevant and useful for evaluating the outcomes of assistive technology and other rehabilitation interventions, particularly those that address activity and participation.

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8

Chapter

Summary and General Discussion

Patricia Rigby

Summary

Chapter 1 describes the rationale for examination of the impact of assistive technology devices (ATDs) on relevant and meaningful outcomes for persons with physical disabilities. The challenges in selecting appropriate outcome measures are discussed. The conceptual underpinnings for this thesis are presented in relation to current rehabilitation practice. These include the International Classification System for Functioning Disability and Health (ICF), the Person-Environment-Occupation Model, and the client and family-centred perspective.

Chapters 2-4 are grouped together in **Section 1**. In these chapters the Canadian Occupational Performance Measure (COPM), and the caregiver assistance scale (adapted from the Pediatric Evaluation of Disability Inventory (PEDI) are used to evaluate the impact of novel seating technologies for children with cerebral palsy (CP). In **Chapters 2 and 3** the results of a study that evaluated the impact of a wheelchair-mounted rigid pelvic stabilizer (RPS) on childrens' perceptions of their activity performance, and the level of caregiver assistance required to perform specific activities are reported. This 11-week study used a within-subject A1-B-A2 design with six children with spastic CP (mean age of 10.4 years) and their mothers. During the two baseline phases of 3 weeks (A1 and A2) the children used their wheelchair lap belt for pelvic stabilization in their chairs, and during the 5-week intervention period the children used the RPS intervention in their wheelchairs. The outcome measures were administered at the end of each of the 3 study phases.

In **Chapter 2** the COPM was used for the first time in assistive technology outcomes research. We chose the COPM to test the clinical assumption that by providing the spastic child with a stable base of support, the child would have greater volitional control for activities involving reaching and bimanual control. With this tool, each child and mother dyad identified 5 activities that the child had difficulty doing from the wheelchair. Study results showed that all children rated improvements in performance and satisfaction with their performance for these specific activities.

In **Chapter 3** we report on the level of caregiver assistance required by each child to perform the activities that they had identified on the COPM. We used the 6-point caregiver assistance scale from the PEDI. The scores range from child is independent to child needs total assistance. We also called the children's mothers weekly, and asked them to comment on their child's activity performance. Their comments were used to explain and corroborate the COPM and caregiver assistance ratings. Caregiver assistance decreased for only 30% of the activities during the intervention phase. However, this scale may not have been sensitive to more subtle changes in the child's need for help while the child gained competency doing the identified activities. Nonetheless the coupling of the caregiver assistance scale with the activities identified on the COPM is a promising strategy for future research to evaluate ATD outcomes, and for outcome evaluation in a clinical setting.

We used a within-subject A1-B-A2 design again in **Chapter 4**. For this study, we enrolled 30 young children with CP and used the COPM to evaluate the impact of two adaptive seating devices (one for seated postural support on the floor or on a chair, the other for support on a toilet) on their children's activity performance within the home. The purpose was to examine whether a stable seated posture enhanced children's abilities to perform self-care and play activities. The mothers also kept a home activity log (HAL) biweekly to describe their children's activity performance. Results showed both statistically significant and clinically important improvements in activity performance and performance satisfaction when the children used the seating devices. We concluded that the adaptive seating devices enabled young children with CP to engage in self-care and play activities, and that the COPM was a responsive and useful measure for ATD outcomes research.

In **Section 2,** comprised of **Chapters 5-7,** the focus was on the evaluation of the impact of electronic aids to daily living (EADL). This technology is designed to enable persons with severe motor impairments, such as spinal cord injury (SCI) tetraplegia to use electronic devices, such as telephones, door openers and home entertainment systems, for various daily activities, e.g., social calls to friends, going out for a visit, and watching TV. We studied the impact of EADL on activity performance and quality of life.

In **Chapter 5** the Lincoln Outcome Measure for Environmental Controls (LOMEC) and the Psychosocial Impact of Assistive Devices Scale (PIADS) were used to evaluate the impact of EADL on functional abilities, psychosocial well-being and quality of life (QOL). We included 32 adults with SCI tetraplegia (16 EADL users and a comparison group of 16 non-users). The EADL users gave significantly higher scores on 75% of the LOMEC items. However, because this was a new tool developed for a clinical program the measurement properties had not been studied, and the tool did not uniformly measure activity performance. The PIADS scores were highly positive and not different for EADL users and non-users. This demonstrated that the anticipated impact of EADLs for non-users was the same as the real psychosocial impact reported by EADL users. However, the PIADS cannot be considered an outcome measure for this form of AT, as it was not able to discriminate the QOL of EADL users from non-users.

Given the need for a good outcome measure to evaluate EADL, **Chapter 6** describes the creation of the Measure of Control using Electronic Aids to Daily Living (MCEADL) and the measurement properties for this new tool. Established procedures were used to generate and gain consensus for the items. For the next step we administered the MCEADL twice (4-8 weeks apart) to 36 adults with SCI tetraplegia (15 EADL users and 21 non-users). Evidence supported the content and discriminative validity, test-retest reliability and internal consistency of the MCEADL. The EADL users scored significantly greater ease with doing activities from their wheelchair and bed, and greater satisfaction for the total MCEADL score and on all four functional domains (home security, communication, comfort and occupation).

In this same study, we examined the impact of EADL on quality of life (QOL) in **Chapter 7**. We wanted to examine the clinical assumption that doing activities with greater autonomy through the help of an EADL would positively influence QOL. We used the Quality of Life Profile for Physical Disability (QOLP-PD) because QOL is defined as the degree to which a person enjoys the important possibilities of his/her life, which we felt was compatible with the goal of EADLs, and because this tool was developed for use with persons with SCI. Our results showed that both groups uniformly rated all aspects of QOL as highly important in their lives. The EADL users rated their satisfaction with QOL significantly higher for total QOLP-PD scores and for 6 of the 9 domains, including all 3 domains of belonging. Findings from both **Chapters 6 and 7** lead us to conclude that using EADLs improves performance and satisfaction with performance of various daily activities by persons with severe motor impairments resulting from SCI tetraplegia and also enhances QOL. Both the MCEADL and the QOLP-PD measured relevant and meaningful outcomes and can discriminate the experiences of EADL users from nonusers. Therefore these tools are useful for clinical purposes and for ATD outcomes research.

General Discussion

The studies conducted for this thesis provide evidence that specific adaptive seating devices and electronic aids to daily living have a positive impact on activity performance, quality of life and caregiver assistance for children and adults with physical disabilities. The measures that were chosen for, or developed for these studies address outcomes that are clinically relevant, and are meaningful to the assistive technology users.

This chapter starts with a review of the importance of assistive technology outcomes research for informing rehabilitation practice, consumer awareness, and policy regarding access and funding for assistive technology devices (ATDs). Assistive technology outcomes research is considered within the context of consumer needs and current funding policies in Canada. Much of this chapter is devoted to a discussion of what was learned from the studies conducted for this thesis. Special attention is paid to the utility of the measures used in our studies with respect to future outcomes research and evaluation of ATDs in clinical practice.

Why is it important to study the effectiveness of assistive technology devices?

Assistive technologies are environmental interventions designed to enable persons with disabilities to gain greater autonomy in doing daily activities, and in turn to improve their quality of life, and reduce the need for caregiver help. However, when we embarked on the research included in this thesis, there was very little empirical evidence to support these assumptions about ATDs. Assistive technologies are typically expensive and there is a need to justify the costs for these devices to governments, insurers and individuals. This is particularly important because ATDs are under prescribed for and under used by clinical populations who need them.

Rehabilitation professionals routinely prescribe ATDs to enable persons with motor impairments (e.g., cerebral palsy and spinal cord injury) to participate in daily activities in their home, school, workplace and community (1). The focus of this thesis has been on ATDs for children with cerebral palsy (CP) and adults with spinal cord injuries (SCI). These clinical populations have the need for many types of ATDs. Thus, it is particularly important to understand their technology needs in relation to their activity goals, and to be guided by the evidence for ATD outcomes for these populations considering that these are large clinical populations. The prevalence of cerebral palsy (CP) is 2-2.5/1,000 population (2) and the prevalence of spinal cord injury is estimated at 200 to 750 per million population (3). In Ontario, Canada there are approximately 46 new SCI's per million population annually (4).

The survey of participation and activity limitations conducted across Canada in 2006 (5), found that people with severe disabilities (e.g., those with spinal cord injuries and cerebral palsy), were the least likely to have all of their needs for assistive technology met. For example, nearly 50% of children who needed ATDs did not have all of their needs met, and just under half of this group had a severe disability (e.g., CP). The most common reason for not getting ATDs was the cost. Family or individuals were responsible for approximately 70% of the costs of devices (for example, in some Canadian provinces there is a cost-sharing for purchase of ATDs; public funding is available for some devices and not for others). In Ontario, the government's Assistive Devices Program (ADP) pays up to 75% of the costs of specific ATDs such as wheelchairs (6), but does not provide support for positioning and seating devices, such as the adaptive seats studied in Part One of this thesis. Nor does ADP fund electronic aids to daily living (EADL), which was the focus for Part Two of this thesis. In most parts of Canada, the onus is on the individual or family to find funding for the ATD interventions studied in this thesis.

The need for ATD outcomes research is well recognized (1, 7-18). As pointed out throughout this thesis, there is a need for evidence of the benefits of ATDs to guide policy for access and funding. This thesis has focused on ATDs that are not currently eligible for public funding in most parts of Canada, and there is limited third party funding available. Thus, in order to influence funding policy for these devices there is a need for outcomes research to demonstrate the impact of these ATDs.

Equally important is the need to provide consumers who can benefit from assistive technologies and clinicians who may prescribe ATDs to address their client's rehabilitation goals with knowledge of ATD outcomes. The knowledge may influence the demand for useful devices (10, 17, 19, 20). Consumers will seek out interventions that they believe will benefit them and their families. Little has argued that consumers today have grown up with a broad range of technology and may consider purchasing assistive technologies much like they would other technologies such as computers, ergonomic furniture and personal digital assistants (10).

Framing assistive technology outcomes research

The International Classification of Functioning, Disability and Health framework (ICF) (21), together with the Person-Environment-Occupation (PEO) Model (22) and the client and family-centred perspective (23, 24) provided the conceptual underpinnings for this thesis, and enabled us to focus the research on outcomes that are both clinically relevant and meaningful to persons with physical disabilities. Both the ICF and the PEO Model guide rehabilitation therapists to focus their interventions on enabling the participation of persons with disabilities in their daily activities and occupations within the environments in which they live, learn, work and play. Furthermore, from a client and family-centred perspective, the focus for interventions should be meaningful to rehabilitation clients.

The primary intent for the research conducted for this thesis was to evaluate the impact of specific adaptive seating devices and electronic aids to daily living on the performance of activities that had meaning and importance in the technology user's daily life. Thus, we started by establishing who the technology was designed for, and what the technology was designed to do. This knowledge helped identify target populations for our studies, and the scope of possible activities that these ATDs could be used for. For example, the adaptive seating devices were designed to provide a stable seated posture from which a young child with cerebral palsy could engage in play and self-care activities; and electronic aids to daily living were designed to allow persons with severe physical impairments to operate electronic devices within their home for security, comfort, communication and various other activities. The PEO Model was particularly useful for conceptualizing how the ATDs influenced the activity performance of the targeted users. The model also helped us to hypothesize about the potential impact of the ATDs on secondary outcomes such as quality of life and caregiver assistance.

Selecting appropriate outcomes measures: How did the tools measure up and what did they tell us about the impact of assistive technology devices?

As mentioned in the introduction to this thesis and throughout the chapters, there were very few appropriate measures available to evaluate clinically meaningful and relevant outcomes when these studies began in the late 1990s. In this section the utility of the measures is examined in relation to the thesis objectives.

A. Evaluating the impact of adaptive seating on the activity performance of children with cerebral palsy

The Canadian Occupational Performance Measure

The Canadian Occupational Performance Measure (COPM) (25, 26) was designed for client-centred practice to evaluate clients' perceptions of change in their performance of a specific set of activities or occupations that have meaning and importance in their daily life. Our study (chapter 2) was the first to use it to evaluate the impact of ATDs on children's activity performance. The COPM has proven to have good reliability and validity, and be responsive to change for various populations across the lifespan (27-32). Recently two publications provide support for the measurement properties of this tool for pediatrics (33, 34). The COPM has been used successfully with child respondents aged 12 years or younger in 14 peer-reviewed publications, including our chapter 2 study, and with children's caregivers in 18 publications between 1997 and 2007 (32). The COPM has comparable structure and is based on similar principles to the Individually Prioritised Problem Assessment (IPPA), which was developed in Europe to assess the effectiveness of assistive technology provision (35). The COPM was a model for the IPPA when it was developed during the broad European Efficiency of Assistive Technology and Services (EATS) study (14). The IPPA has now been used successfully in numerous European assistive technology studies (35) and may provide a good alternative to the COPM for evaluating ATD outcomes.

Data collected from COPM has relevance and meaning to ATD users

The COPM works well because it is an individualized measure. In our studies, the COPM allowed each participant to identify and prioritize activities that were meaningful and relevant to his or her daily life, and targeted actions that can be enabled or produced by the ATD, thus ensuring the information collected had ecological validity. In Chapter 4 we also asked the children's parents to respond biweekly to semi-structured questions about their child's daily behaviours and activity performance in self-care and play on the Home Activity Log, which we developed for the study. Their perspectives helped us interpret the COPM change scores and provided further validation of the COPM findings.

The use of the COPM to evaluate assistive technology interventions

In our experience, a key step when using the COPM to evaluate ATD interventions in research and clinical practice is to frame the identified activities around what the intervention is targeted to do. Others have focused the COPM interview in a similar manner to evaluate word cuing and word prediction software for writing tasks (30, 31) and to evaluate virtual reality games for activities involving the upper extremities (29). We started the COPM interview by having the child or parent identify activities that he or she wants, needs or expects the child to do in the areas of self-care or play, as per the tool's instructions. We asked the respondents to focus on specific activities that the child would do from a seated position. For example, in the Chapter 2 study we asked the children to identify bimanual activities that they would do when using their wheelchair. This allowed us to test the clinical assumption that by providing greater postural stability, children with spastic cerebral palsy would gain more volitional control of their upper extremities for manual activities. While several review articles present evidence that adaptive seating improves postural control (36, 37) and upper-extremity function (38), we were the first to formally evaluate the impact of the seating interventions on activity performance.

COPM results demonstrate benefits of adaptive seating devices

The COPM results in both studies demonstrated that the children (in Chapter 2) and the parents (in Chapter 4) rated the child's activity performance as both clinically and significantly better when the study interventions were used (the rigid pelvic stabilizer in Chapter 2 and the adaptive seats in Chapter 4). They also rated greater satisfaction with activity performance when the interventions were used. We concur with other researchers and conclude that the COPM is a useful, responsive and feasible tool for detecting meaningful changes evaluating the outcomes of ATD interventions for children in clinical settings and for research purposes (29-32, 34, 38, 39).

Benefits to using the COPM for research and clinical practice

There are a number of potential benefits in using the COPM in research and clinical practice. By involving the child and/or parents in identifying and prioritizing selected activities as the focus for the intervention, there is greater likelihood that the child will be provided with or will take opportunities to engage in those activities. This may influence expectations for the child's activity performance and for the ATD, and motivation to use the technology (32, 40). In other words, behaviours may change because they are the focus of study. This possibility could be further examined in longitudinal studies to examine ATD usage over time. A potential limitation for using the COPM is that it is a generic measure of activity or occupational performance, and requires interviewing skill and clear knowledge of activities or occupations that can be enabled by specific ATDs to successfully focus the interview, particularly with children. A good alternative to the COPM for research purposes is the IPPA, as it includes a checklist of activities that ATDs typically target, which would facilitate the identification of problems that an ATD might address (35). However, the COPM may be the better tool in the general clinical setting when children and caregivers first identify activity or occupational performance issues, and a variety of interventions, including assistive technologies, are considered.

B. Evaluating the impact of electronic aids to daily living (EADL) on the activity performance of adults with cervical spinal cord injuries

Generic functional outcomes measures are not well suited to evaluating EADL

In Section 2 of this thesis we needed examined the impact of electronic aids to daily living (EADL) on activity performance. EADL technology is designed to enable persons with severe motor impairments to use specific electronic devices such as telephones, door openers, lights and home entertainment systems for communication, security, comfort, leisure and work. The difficulty with generic measures is that they do not target the specific activities influenced by EADL. The use of two generic functional measures, the Functional

Autonomy Measuring Scale (SMAF) (41) and the Functional Independence Measure (FIM) (42) identified that generic measures could establish that the two groups in our studies (EADL users and non-users) had comparable levels of disability. However, the functional activities included in the measures were not influenced by the functions of EADLs, except for the IADL subscale of the SMAF.

The Lincoln Outcome Measure for Environmental Controls

We used the Lincoln Outcome Measure for Environmental Controls (LOMEC) in Chapter 5. Results demonstrated that EADL users gave significantly higher scores for 75% of the LOMEC items compared with non-users. The non-users were either not able to, or had difficulty doing most of the activities on the LOMEC, whereas the EADL users reported that they could do most activities well. However, this tool had weaknesses. There were individualized 3-point nominal scales for each of the 12 items in this measure, and they inconsistently included combinations of ability to do an activity, satisfaction with ability, and whether the respondent's functional needs had been met by the EADL. We felt that this tool was not uniformly measuring activity performance.

Development of the Measure of Control Using Electronic Aids to Daily Living

In Chapter 6 we revised the LOMEC for clinical and research purposes, by modifying the items and the measurement scales. The tool was renamed the Measure of Control using Electronic Aids to Daily Living (MCEADL) and it contained 4 subscales, home security, communication, comfort and occupation. We included four 7-point scales for rating: 1) importance, 2) ease of performing tasks from bed, 3) ease of performing tasks from wheelchair, and 4) satisfaction with performance of each task.

We established the content validity, internal consistency, and test-retest reliability for the MCEADL. Findings from Ripat's study provide further validation of the contents of the MCEADL (43). Ripat administered the COPM to 46 EADL users and asked each of them "what are some of the activities that you need, want or would like to use your EADL for." She grouped the 67 identified activities into the following 6 categories: independence (e.g., door openers), entertainment, communication of basic needs, socialization with family and friends, to meet safety needs, productivity, and other. The items and categories are very similar to those on the MCEADL, which lends support to the content validity of the MCEADL. Thus, we conclude that the MCEADL shows great promise as an outcome measure for clinical and research applications to evaluate EADL interventions.

MCEADL results show positive impact of EADL on activity performance

The significantly higher MCEADL total and domain scores reported by the EADL users demonstrated that this technology does improve ease of performance and satisfaction with performance of various daily activities by persons with severe motor impairments resulting from spinal cord injury tetraplegia. The results demonstrated that the MCEADL can detect statistically significant differences in ease of performance and satisfaction with performance between the two groups. Plus, the EADL users and nonusers rated all items equally as very important, which demonstrates not only that the items on the MCEADL are meaningful to persons with severe motor limitations, but also that the functions enabled by EADLs are of great importance to them.

C. Evaluating the impact of assistive technology devices on secondary outcomes of interest

A secondary goal for this thesis was to examine clinical assumptions about the influences of assistive devices on quality of life and caregiver burden.

The impact of adaptive seating on the need for caregiver assistance

In Chapter 3 we used the 6-point caregiver assistance scale from the PEDI (44) and asked mothers to rate the amount of caregiver assistance their child needed when performing each of the five activities the child had identified on the COPM. Caregiver assistance showed only modest change (caregiver assistance was significantly lower for only 30% of the activities) when the seating intervention was used in this study. We used this same strategy again in the study conducted for Chapter 4, where we asked the mothers to rate the caregiver assistance needed to help their children do the activities identified on the COPM. We found that caregiver assistance was reduced when the intervention seats were used. We are preparing a manuscript for publication with these results. We feel that this assessment strategy has merit for both clinical and research purposes, because it is an individualized approach and the activities are relevant to the child and family. Even though the PEDI as a whole has very good measurement properties (44, 45), the reliability of the modified caregiver assistance scales, as used in our study, need to be examined.

Measuring quality of life: The Psychosocial Impact of Assistive Devices Scale

We used the Psychosocial Impact of Assistive Devices Scale (PIADS) (46) to evaluate the impact of EADL on QOL in Chapter 5. This tool was developed to measure the perceived impact of all types of ATD on functional independence, well-being and quality of life (46). Our results for Chapter 5, and results from an earlier study with persons with muscular dystrophy (47) both show that the anticipated impact of EADL by nonusers and the real impact as rated by the EADL users was equally positive. This is a useful finding, as it demonstrates that persons with severe physical disabilities have very high expectations about the benefits of EADL, whether or not they are using an EADL system. However, because of the way the PIADS interview is structured it does not have the capability of capturing differences in QOL between EADL users and nonusers, nor change in quality of life before and after provision of EADL.

Measuring quality of life: The Quality of Life Profile for Physical Disability

Thus, for Chapter 7 a generic evaluative measure of QOL that was developed for persons with SCI and focuses on areas of QOL that have the potential to be influenced by using EADLs was used. From a large pool of QOL measures used in rehabilitation, we felt the Quality of Life Profile for Physical Disability (QOLP-PD) (48) would fulfill these purposes. Both the EADL user group and nonuser groups uniformly rated the elements of quality of life included in this measure as very important in their lives. These findings support the content validity of this measure of quality of life for this population. The measure also demonstrated the ability to discriminate differences in QOL between EADL users and nonusers, which provides confidence that the measure may be responsive to change when used before and after the provision of EADL. The EADL users rated their levels of satisfaction with quality of life significantly higher than nonusers on the total QOLP-PD score, and in 6 of 9 domains on this tool. The ease with which EADL users were able to engage in activities around their homes appears to be associated with greater satisfaction with various aspects of QOL, including physical and spiritual being, physical belonging, and with the possibilities of achieving personal goals, hopes and aspirations (in the becoming domain on the QOL-PD) (48, 49).

D. Summary of the merits of the outcome measures used in this thesis

In Table 1 the merits of the measures used in the studies included in this thesis based on criteria that many researchers agree are important when evaluating ATD outcomes in clinical settings and in research are summarized (19, 50-53). These criteria suggest that ATD outcome measures should:

- be sensitive and specific to the effects of the ATD intervention (i.e., be clear what the purpose of the technology is, and what it is designed to do),
- be appropriate for the chosen population for the study,
- include outcomes that are meaningful and relevant to the client/ATD user and to his/her rehabilitation goals,
- reflect performance in the user’s environment (rather than measuring capacity within a standardized setting),
- reflect the user’s perception of his or her performance, as this will affect the user’s willingness to use the technology at home and in the community,

- demonstrate good measurement properties, including reliability, validity and responsiveness to change or differences in performance.

Likelihood of continued ATD usage

Favourable outcomes associated with ATDs can influence and possibly even predict the continued usage of the ATD interventions included in this thesis (52, 54-56). The measures that we used focused on outcomes that were meaningful and relevant to the study participants. With the COPM the children and mothers identified activities that had meaning and relevance to them, and rated the importance of these activities for their daily lives. Caregivers rated the level of assistance the children needed for these same activities. The EADL users and non-users gave uniformly high ratings to the importance of the MCEADL and the QOL-PD items to their daily lives. Plus, the study participants were rating the effect of the ATDs within the environment in which they were using the devices. If the device meets expectations, several authors have argued that the user will be more motivated and more likely to continue to use the device (17, 19, 56). This appeared true for two of our studies. When we offered the adaptive seating interventions to families after they completed the Chapter 4 study, 83% of the families kept at least one device, while 63% of families kept both devices. In Chapter 7 we reported that all EADL users continued to use their devices to full capacity on a daily basis (for a mean of 6 years, range of 2-20 years), which is consistent with the findings of others (57).

This reasoning is consistent with concepts presented in the model developed by Lenker and Paquet (17) to predict the future use of assistive technologies. They argue that people are more likely to try an assistive device if they perceive that the device will help them to do things that they want to do and contribute to their quality of life. Positive experiences using a device, and the device meeting expectations will likely lead to continued use of the device.

Clinical Relevance

The findings from the research conducted for this thesis have immediate and significant relevance to rehabilitation practice with children and adults with physical disabilities. Knowledge generated about the positive impact of the ATDs studied in this thesis on activity performance, QOL and caregiver assistance should give therapists confidence to prescribe these technologies to meet the needs of their clients. The COPM has proven to be responsive to change in activity performance. The PEO model, as used in the introductory chapter, can help to frame the COPM interview within the ATD clinic situation, and guide assessment and intervention practices to focus attention on the person-environment-occupation relationship. This would help to ensure that the ATD prescription can target relevant and meaningful goals for users. In addition, the MCEADL and QOLP-PD discriminate differences in activity performance and QOL between EADL users and non-users, and this gives confidence that they will also be responsive to change in these areas, when used before and after the provision of EADL. Thus we also recommend these two tools for outcomes evaluation in the clinical setting.

Future Directions and Knowledge Translation

There is a need to build on the work that has been done for this thesis in order to establish the cost-effectiveness of assistive technologies. A mix of research designs can help to advance our understanding of the outcomes of ATD interventions (16, 58). While randomized controlled trials have rarely been done in ATD research, this design should be considered, particularly to evaluate new assistive technologies. Longitudinal studies are also needed to examine the impact of ATDs over time on activity and participation and on other outcomes of interest such as impact on family, and on the user's personal growth and achievements. It seems reasonable to postulate that being enabled by ATDs may give ATD users greater expectation and motivation to do more for themselves towards achieving greater autonomy. The usage of ATDs may also lead to greater participation in life experiences. For example, in our Chapter 4 study during the HAL interview, some families talked about using the activity seat in restaurants or the homes of family and friends. They saw opportunities for using the ATD in various aspects of family life.

The outcome measures used in these studies have proven to be useful and feasible for AT outcomes research and clinical practice. The COPM is already quite widely used for rehabilitation research (27, 32) and AT outcomes research (29-31). The test-retest reliability of the pairing of the caregiver assistance scale from the PEDI with the COPM should be investigated. Plus, we recommend examining the responsiveness of the MCEADL and QOLP-PD to change.

The findings for the studies in this thesis have been disseminated through peer-reviewed publications. In addition, the findings from this research have been shared with consumers through personal letters and lay publications, with rehabilitation clinicians and researchers at clinical practice forums, as well as professional and scientific meetings, and with policy makers though meetings and reports. Further knowledge dissemination is needed to ensure clinicians, consumers and policy makers are made aware of the benefits of the ATDs studied in this thesis, and to make clinicians and researchers aware of the utility of the outcome measures that were used in these studies.

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Table 1: How well do measures used in studies meet criteria for clinical relevance and meaningfulness

Measurement Criteria	**COPM**	**COPM & CGA**	**MCEADL**	**PIADS**	**QOL-PD**
Sensitive and specific to the effects of the ATD intervention	Generic activity/ occupation measure; interviewer requires knowledge of purpose of the ATD	Partly, as CGA is linked to activities on COPM	Yes - Device specific measure	Yes – ATD generic measure	No – generic measure; however use of ATD can impact many aspects of QOL on scale
Appropriate for the chosen population for the study	Yes; can be applied across lifespan	Yes	Yes	Yes	Yes
Outcomes have relevance and meaning to ATD users	Client identified activities of interest; client rates importance of activities to daily life	Yes because linked to COPM	Focuses on common daily activities; client rates importance of items to daily life	Content established by ATD users	Yes – content established by persons w SCI; reflected by ratings of importance
Reflects experiences within user's environment	Yes – activities performed at home, school or community	Yes – within daily life	Yes – in home setting	Yes – within daily life	Yes – within daily life
User's perception	User rates performance & satisfaction with performance	Caregiver rates level of assistance provided	User rates ease of performance & satisfaction with performance	User rates psychosocial impact of ATD	User rates satisfaction, control & opportunities in daily life
Good measurement properties	Established validity & reliability; responsive to change	Yes for CGA with PEDI; not established when linked with COPM	Preliminary evidence of reliability and content, ecological & discriminative validity	Established validity and reliability	Preliminary evidence of reliability and validity

Nederlandse Samenvatting

(Dutch summary)

Samenvatting (in Dutch)

Hoofdstuk 1 beschrijft het principe van onderzoek naar het effect van technische hulpmiddelen 'assistive technology devices' (ATDs) op relevante en belangrijke uitkomsten bij personen met lichamelijke beperkingen. De tijdens de selectie van bruikbare uitkomstmaten aangegane uitdagingen worden besproken. De conceptuele onderbouwing van dit proefschrift is afgestemd op de huidige revalidatiepraktijk. Deze behelst de 'International Classification System for Functioning Disability and Health' (ICF), de 'Person-Environment-Occupation Model' en de 'client and family-centred perspective'.

Hoofdstukken 2 tot 4 zijn in **rubriek 1** bijeengebracht. In deze hoofdstukken worden de 'Canadian Occupational Performance Measure' (COPM) en the 'caregiver assistance scale' (een gewijzigde versie van the 'Pediatric Evaluation of Disability Inventory' (PEDI)) gebruikt om het effect van nieuwe steunvlaktechnieken voor kinderen met cerebrale parese (CP) te evalueren. In de **hoofdstukken 2 en 3** worden de resultaten besproken van een onderzoek waarin het effect van een op een rolstoel gemonteerde 'rigid pelvic stabilizer' (RPS) op de eigen perceptie van de fysieke prestaties van kinderen en de mate van vereiste begeleiding door een hulpverlener om specifieke activiteiten uit te voeren, geëvalueerd. In dit 11 weken durend onderzoek werd een intra-proefpersoon A1-B-A2 opzet toegepast bij zes kinderen met spastische CP (gemiddelde leeftijd 10,4 jaar) en de moeders van de kinderen. Tijdens de twee aanloopfasen van 3 weken (A1 en A2) gebruikten de kinderen hun rolstoelschootriem om hun bekken in de rolstoel te stabiliseren en tijdens de 5 weken durende interventieperiode gebruikten de kinderen de RPS-interventie in hun rolstoelen. De uitkomstmaten werden aan het einde van elk van de 3 onderzoeksfasen toegepast.

In **hoofdstuk 2** werd de COPM voor de eerste keer gebruikt voor onderzoek naar uitkomsten van technische hulpmiddelen. Wij kozen de COPM om de klinische veronderstelling te testen dat het kind door een stabiel steunmechanisme meer vrijwillige controle zou hebben om activiteiten op het gebied van reiken en bimanuele besturing uit te voeren. Met dit meetinstrument stelde elk kind-moeder-koppel 5 activiteiten vast die het kind slechts met moeite kon uitvoeren vanuit de rolstoel. Uit onderzoeksresultaten bleek dat alle kinderen verbeteringen van en tevredenheid met hun prestaties tijdens deze specifieke activiteiten vaststelden.

In **hoofdstuk 3** presenteren wij onze bevindingen op het gebied van de voor elk kind vereiste mate van begeleiding door de hulpverlener om de activiteiten die zij op de COPM vaststelden, uit te voeren. Wij gebruikten de 6-punts 'caregiver assistance scale' uit de PEDI. De gevonden scores liggen tussen 'kind is onafhankelijk' en 'kind kan niet zonder volledige begeleiding'. Wij hebben de moeders tevens wekelijks gebeld om hen te vragen commentaar te geven op de fysieke prestaties van hun kind. Deze reacties werden gebruikt om de scores op de COPM en begeleiding door de hulpverlener uit te leggen en te bevestigen. Tijdens de interventieperiode werd een vermindering van slechts 30% gemeten voor de activiteiten door de hulpverlener. Deze schaal zou echter misschien niet in staat zijn om de subtielere veranderingen te registreren in de behoefte van het kind aan hulp tijdens de fase waarin het kind vaardigheid verwierf bij de vastgestelde activiteiten. Dit neemt echter niet weg dat de koppeling van de 'caregiver assistance scale' met de op de COPM vastgestelde activiteiten een veelbelovende strategie is voor toekomstig onderzoek om ATD-uitkomsten te evalueren en voor evaluatie van uitkomsten in een klinische setting.

In **hoofdstuk 4** gebruikten wij wederom een intra-proefpersoon A1-B-A2 opzet. Wij hebben 30 jonge kinderen met CP tot dit onderzoek toegelaten en wij hebben de COPM gebruikt om de invloed van twee adaptieve steunvlakhulpmiddelen (één voor steun in zittende houding op de vloer of op een stoel, de ander voor steun op het toilet) op de fysieke prestaties van hun kinderen binnenshuis te evalueren. De bedoeling van dit onderzoek was om na te gaan of een stabiele zithouding zou bijdragen tot een verbetering van de bekwaamheden van de kinderen op het gebied van zelfhulp en spel. De moeders hielden tevens een tweewekelijks thuisactiviteit-logboek (HAL) bij waarin zij de fysieke prestaties van hun kinderen beschreven. De resultaten toonden zowel statistisch significante als klinisch belangrijke verbeteringen van de fysieke prestaties aan, evenals voldoening door prestaties wanneer de kinderen de steunvlakhulpmiddelen gebruikten. Wij concludeerden dat de adaptieve steunvlakhulpmiddelen jonge kinderen met CP in staat stelden om zelfhulp- en speelactiviteiten te ontwikkelen en dat de COPM een responsieve en bruikbare maat is voor ATD-uitkomstonderzoek.

In **rubriek 2,** bestaande uit de **hoofdstukken 5-7,** ligt het accent op de evaluatie van het effect van 'electronic aids to daily living' (EADL). Het doel van deze technologie is personen met ernstige motorische beperkingen, zoals tetraplegie door ruggenmergletsel (SCI) in staat te stellen om elektronische apparaten te gebruiken, bijvoorbeeld de telefoon, deuropeners en systemen voor vermaak en ontspanning in de huiselijke sfeer, voor diverse dagelijkse activiteiten, zoals gesprekken met vrienden, op bezoek gaan bij iemand en televisie kijken. Wij onderzochten het effect van EADL op fysieke prestaties en kwaliteit van leven.

In **hoofdstuk 5** werden de 'Lincoln Outcome Measure for Environmental Control' (LOMEC) en de 'Psychosocial Impact of Assistive Devices Scale' (PIADS) gebruikt ter evaluatie van het effect van EADL op functionele vermogens, psychosociaal welzijn en kwaliteit van leven (QOL). Wij hebben 32 volwassenen met tetraplegie door ruggenmergletsel (16 EADL-gebruikers en een controlegroep van 16 niet-gebruikers) tot het onderzoek toegelaten. De EADL-gebruikers noteerden significant hogere scores op 75% van de LOMEC items. Daar dit instrument echter pas onlangs was ontworpen voor een klinisch programma, waren de meeteigenschappen ervan nog niet onderzocht en bleek dat het instrument geen uniforme meting van de fysieke prestaties aangaf. De PIADS scores waren zeer positief en er bleek geen verschil tussen EADL-gebruikers en niet-gebruikers. Dit toonde aan dat het verwachte effect van EADL’s bij niet-gebruikers niet verschilde van het werkelijke psychosociale effect dat door de EADL-gebruikers werd gerapporteerd. De PIADS kan echter niet als een uitkomstmaat beschouwd worden voor dit type AT, omdat deze niet in staat was om de QOL van EADL-gebruikers te onderscheiden van die van niet-gebruikers.

Vanwege de behoefte aan een goede uitkomstmaat voor evaluatie van EADL wordt in **hoofdstuk 6** de ontwikkeling van de ‘Measure of Control using Electronic Aids to Daily Living’ (MCEADL) en de meeteigenschappen van dit nieuwe instrument beschreven. Bewezen procedures werden toegepast om de items te ontwikkelen en consensus voor de items te bereiken. Daarna hebben wij de MCEADL tweemaal toegepast (met een tussenpoos van 4-8 weken) bij 36 volwassenen met tetraplegie door ruggenmergletsel (15 EADL-gebruikers en 21 niet-gebruikers). De resultaten bevestigden de discriminerende en inhoudelijke validiteit, test-hertest betrouwbaarheid en interne consistentie van de MCEADL. De EADL-gebruikers ervoeren een significante toename van het gemak waarmee zij activiteiten vanuit hun rolstoel en bed konden uitvoeren en meer voldoening op de MCEADL totaalscore en op alle vier functieonderdelen (veiligheid in huis, communicatie, comfort en bezigheid).

In hetzelfde onderzoek controleerden wij welk effect EADL had op de kwaliteit van leven (QOL) in **hoofdstuk 7**. Wij wilden nagaan of de klinische veronderstelling dat het verrichten van activiteiten met meer autonomie, dankzij de assistentie van een EADL, een positieve invloed op de QOL heeft, op waarheid berust. Wij gebruikten de ‘Quality of Life Profile for Physical Disability’ (QOLP-PD), omdat de kwaliteit van leven (QOL) wordt gedefinieerd als de mate waarin een persoon de belangrijke mogelijkheden van zijn/haar leven geniet, wat volgens ons strookt met het doel van EADL’s, en tevens omdat dit meetinstrument is ontwikkeld voor gebruik bij personen met ruggenmergletsel. Onze resultaten toonden aan dat beide groepen alle aspecten van QOL op eenparige wijze waardeerden als zijnde bijzonder belangrijk in hun leven. De EADL-gebruikers gaven hun tevredenheid met QOL een significant hogere score op totale QOLP-PD scores en op 4 van de 9 domeinen, inclusief alle 3 domeinen van ‘erbij horen’. Bevindingen afkomstig zowel van **hoofdstuk 6 als hoofdstuk 7** rechtvaardigen de conclusie dat het gebruik van EADL’s prestaties en tevredenheid met prestaties op het gebied van diverse dagelijkse bezigheden door personen met ernstige motorische beperkingen tengevolge van tetraplegie door ruggenmergletsel verbetert en de QOL ook op een hoger niveau brengt. Zowel de MCEADL als de QOLP-PD bleek in staat relevante en belangrijke uitkomsten te meten en de ervaringen van EADL-gebruikers te onderscheiden van die van niet-gebruikers. Hieruit volgt dat deze meetinstrumenten van nut zijn voor klinische doeleinden en ATD-uitkomstonderzoek.

Hoofdstuk 8 behelst een algemene discussie en conclusies voor dit proefschrift. Bevindingen uit onderzoek worden besproken in het kader van behoeften van de consument en huidige gedragslijnen met betrekking tot fondsgelden in Canada. De toepasbaarheid van de meetinstrumenten die in onze onderzoeken zijn gebruikt worden beoordeeld met betrekking tot toekomstig uitkomstonderzoek en evaluatie van ATD’s in de klinische praktijk.

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Curriculum Vitae

Patricia Jean Rigby was born on July 26, 1955 in Saskatchewan, Canada. She worked as an Occupational Therapist in Canada and Australia for 13 year with children, adults and older adults with neurological impairments. This lead to her interest in research, and in 1991, Patricia graduated with a Masters Degree in Health Sciences from McMaster University in Hamilton, Ontario. Patricia then worked as a research assistant in the School of Rehabilitation Sciences at McMaster University and at the Bloorview MacMillan Children’s Centre in Toronto. In the mid-1990’s Patricia became an investigator on research projects involving assistive technology and environmental assessment, and became the Occupational Therapy Research Coordinator at Bloorview. Her work has focused on advancing occupational therapy practice, and innovation in assistive technologies for persons with physical disabilities. She became a Lecturer in the Department of Occupational Science and Occupational Therapy at the University of Toronto in 1994 and was promoted to Associate Professor in 2007. She is now a Scientist in the Bloorview Research Institute at Bloorview Kids Rehab, Toronto. In 2008, Patricia received the prestigious Circle of Honour Award for Education at Bloorview in recognition of her teaching and mentorship in occupational therapy and pediatric rehabilitation. She also received the Research Supervisor Award in the Department of Occupational Science and Occupational Therapy from the University of Toronto. Patricia has published extensively in peer-reviewed journals, has co-edited a textbook and has written numerous book chapters. She has also presented her work internationally. Patricia currently lives in Toronto, Ontario with her husband, John Wedge.

Additional Publications

Additional Publications

Books Edited

1. Letts, L., **Rigby, P**. & Stewart, D. (Eds.) (2003) *Using environments to enable occupational performance*. Thorofare, NJ: Slack Inc.

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