BRIEF REPORTS

Impact of Long-term Use of Adaptive Seating Device on Children with Cerebral Palsy and their Families in Mumbai, India

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ABSTRACT

Purpose: *There is evidence that adaptive seating devices can play a major role in the positioning and support of children with cerebral palsy (CP), and be of great benefit to them and their families. This study aims to provide preliminary information on the impact of long-term use of seating devices on the functional life of children with cerebral palsy.*

Method: *Family Impact of Assistive Technology Scale (FIATS) was used to assess the impact of the seating device among children with cerebral palsy. The study participants consisted of 15 parents (9 mothers and 6 fathers) of 15 young children (12 males and 3 females) with cerebral palsy. On the basis of Gross Motor Function Classification System (GMFCS), 1 child at level III, 7 children at level IV, and 7 children at level V were included in the study. Mean age of the children was 5 years, and the mean duration of use of adaptive seating was 13 months.*

Results: *It was found that the uninterrupted use of adaptive seating devices had an overall positive effect on the lives of families of children with GMFCS levels III, IV and V as measured by FIATS. The greatest benefits were in relation to the children's social interactions, the acceptance of assistive technology by parents, feeling of contentment among children, and the degree of autonomy over their own activities and in the performance of these activities independently.*

Conclusions: *From the perspective of parents, FIATS is a measurement instrument that focusses on domains that give quantitative descriptions of a wide range of seating devices when used in a child's home environment. Use of*

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FIATS helps therapists to take a judicious approach regarding long-term use of seating devices. Parents' perceptions can help in this process.

Key words: *FIATS, parents' perceptions, GMFCS.*

INTRODUCTION

Cerebral Palsy (CP) is a non-progressive lesion of the immature brain that results in impairment of movement and postural control. Many children with CP cannot sit without support, and occupational therapists routinely prescribe adaptive seating devices to promote their function and improve their developmental capabilities (Rigby et al, 2009). Parents who have young children with complex physical disabilities face challenges that are both physically and emotionally demanding (Ryan et al, 2007). The care and direct supervision required by children with physical disabilities such as cerebral palsy, only increases as they grow older. This added caregiver burden could lead to serious health problems for parents and other family members (Ryan et al, 2006). Adaptive equipment, in addition to having direct therapeutic benefits, can play an important role in care giving and parenting by assisting in the daily management of the child at home (Tecklin, 2008). Assistive technology may also play a role in mitigating caregiver stress and burden by improving functional performance, social interaction and autonomy in children with physical disabilities (Ryan et al, 2006). If the needs of the child's care providers are taken into consideration, the therapist may provide equipment that is likely to be used more effectively (Kramer, 1999).

It is important for rehabilitation clinicians to adopt and use measures that are sensitive to the impact that enabling interventions like assistive devices have on family life. The Family Impact of Assistive Technology Scale (FIATS) is a measure to detect the multidimensional effect of assistive device use on families of young children with disabilities (Ryan et al, 2006; Ryan et al, 2007). Ryan (2006, 2007) studied the internal consistency, test- retest reliability, content validity and face validity and concluded that FIATS is a homogenous and reproducible multidimensional measure of dimensions of child and family life.

Interprofessional Practice and Clinical Standards (2004) defines long-term use as the use of seating /mobility equipment for more than 6 months. For the device to be useful in the long term, it should fulfil certain criteria like comfort, function, cost, durability, appearance, weight, size and manageability. The user may have problems with adaptive aids if these criteria are not met and if the device does not work well in the client's primary environment. The factors that make the device more usable in the long term need to be explored (Kramer, 1999; Tecklin, 2008).

Objective

At the leading rehabilitation Centre in Mumbai, India, the Cerebral Palsy chair is prescribed for children with GMFCS levels III, IV and V to improve postural control and to aid in enhancing functional skills. Benefits from seating devices have been reported to the Centre by urban slum dwellers, but long-term usefulness and satisfaction have not been studied. Research is needed to develop evidence-based data regarding the factors that contribute to the continuing use of the seating device. The device should be evaluated to determine its impact on the client's functional life. A survey was therefore conducted to gauge the usefulness of the CP chair and to assess the satisfaction of parents after long-term use of the device.

METHODS

Participants

Convenience sampling was done from among the clients of the rehabilitation center in Mumbai. Sample size was calculated using the formula for sample less than 30 ($t \times SD/\sqrt{N}$) with estimate of 95% confidence level and average positive response rate between 5.5% and 4% (Hicks, 2004). Eligible families had children who (a) had a primary diagnosis of CP with a functional status defined by Gross Motor Function Classification System (GMFCS) levels III, IV and V and (b) were between 2 and 7 years of age. The cerebral palsy chair is commonly used by children in this age group because it offers firm support, unlike the corner chair used by children below 2 years of age. The wheelchair is preferred after the age of 7 because it enables outdoor mobility and parents find it easier to handle.

Screening interviews were conducted to identify and recruit parents who (a) were primary caregivers of the child, where primary caregiver was defined as an adult who provided at least 10 hours of direct supervision per day; and (b) whose child had used the Cerebral Palsy chair for more than 6 months.

The purpose of the study was explained and expectations of participants during their visit were emphasized. Therapists clarified doubts expressed by the caregivers.

Adaptive Seating Device

All the participants had received the custom-made Cerebral Palsy (CP) chair from the Centre (Figure 1) and had used it for more than 6 months. The CP chair is fabricated from wood, which made it durable and comfortable, and was inexpensive as compared to the ones available in the market. CP chair with accessories as per the client's body dimensions and feasibility for some future growth (Tecklin, 2008) were prescribed. All CP chairs had a lapboard, foot support, chest strap and pelvis strap. Other components varied according to specific needs, such as head support, seat cushion, abductor wedge, castor wheels, and shoulder harness, among others. On receiving the CP chair, its use and precautions were explained to the caregivers of the 15 participants.

Figure 1- Cerebral Palsy chair with accessories

The lapboard provides the child with a stable surface on which to eat and play. It is positioned at elbow height for comfort and to assist external stability. A 'U'-shaped or lateral head support is provided to keep the head in midline. Cushions made of foam encourage upright posture and prevent the user from sliding forward in the chair owing to muscle tone abnormalities. Abductor wedge is provided at the distal end of the thigh to maintain the alignment of the hips and knees and inhibit adduction and internal rotation (Howison, 1983; Finnie, 1997; Werner, 1999; Levitt, 2004).

Questionnaire

The English version of Family Impact of Assistive Technology Scale – FIATS - was used for this study. To help parents understand and read questions easily, the English version was translated to Hindi, the local language. Back translation from Hindi to English was done for confirmation. Both the steps of translation were done by a language expert. Although reliability and validity testing were not done for the translated version, FIATS is a standard tool with established acceptable internal consistency and test-retest reliability.

The questionnaire was hand-delivered to 18 parents and they were given 1 week to complete it. 15 parents – 9 mothers and 6 fathers - returned the completed questionnaire.

The Family Impact of Assistive Technology Scale assessed the impact of assistive technology device use on the lives of children with physical disabilities and their families. FIATS measures this impact by 9 related constructs (subscales) that include: child autonomy, caregiver relief, child contentment, doing activities, parent effort, family and social interaction, caregiver supervision, safety and technology acceptance. These constructs tap into aspects of child and family life that assistive technology devices may influence, such as the degree to which a child can perform activities independently (autonomy), interacts with others (family and social interaction), and requires attention from family members (supervision). Overall, the 9 subscales contribute 64 items to the FIATS. The FIATS included a 7-point Likert scale to record the degree to which parents agreed or disagreed with each statement (7 - Strongly agree, 6 - Agree, 5 - Somewhat agree, 4 - Neither Agree nor Disagree, 3 - Somewhat Disagree, 2 - Disagree, 1- Strongly Disagree). The overall range of FIATS scores was from 64 - 448.

Scoring on FIATS is calculated by the sum of the means of the 9 related subscales. Lower FIATS scores are associated with lower child and family functioning on these dimensions. Higher scores suggest an overall positive impact on child and family life as defined by these constructs.

Data Analysis

Table 1 gives demographic details of children included in the study with total

FIATS score according to GMFCS level. The mean age of the children was 5 years, the youngest being 3 years and 4 months old and the eldest being 7 years old. There were 3 girls and 12 boys. The duration of seating device use ranged from 7 months to 22 months. The mean duration of use therefore was 13 months. As per the GMFCS classification, there was 1 child who was functioning at level III, while there were 7 children functioning at level IV and 7 children at level V. The FIATS scores of the 15 children ranged from 175 to 312. The FIATS scores of the 7 level IV children ranged from 175 to 312, and of the 7 level V children from 195 to 275. Mean score of level IV children was 249 and of level V children was 238. Table 2 shows mean score of 9 FIAT domains in children with levels IV and V children GMFCS. Table 3 shows mean and standard deviation of all the 15 children's FIATS domains. Mean values in the domains of social interaction, contentment, technology acceptance, doing activities and autonomy were more than the mean values of supervision, caregiver relief, safety and effort.

Table 1: Demographic details of the Participants with total FIATS score

Sr. no.	Age	Sex	Duration of CP chair use	GMFCS Level	Total FIATS score
1	3.4	M	8 MTH	IV	246
2	3.7	F	7MTH	V	195
3	3.10	M	1.2YR	V	229
4	4	M	1YR	IV	253
5	4	M	7MTH	IV	175
6	4.6	M	11MTH	V	227
7	4.6	M	1.4YR	IV	312
8	4.8	M	8MTH	IV	271
9	5.4	M	1.6YR	V	275
10	5.5	M	1.8YR	IV	261
11	5.10	F	1.8YR	V	258
12	6	M	1YR	V	245
13	6.5	M	1.I0	III	270
14	7	F	1YR	V	240
15	7	M	1.I0YR	IV	229

Table 2: Mean scores of FIATS domains according to GMFCS levels IV and V

FIATS DOMAIN	MEAN SCORE LEVEL IV(n-7)	MEAN SCORE LEVEL V(n-7)
Social Interaction	20	17
Supervision	20	21
Caregiver Relief	31	24
Contentment	37	32
Safety	23	23
Technology Acceptance	50	49
Effort	26	25
Doing Activities	22	21
Autonomy	21	18

Table 3: Mean and Standard Deviations: FIATS Domain Statistics

FIATS DOMAIN	Number of questions in each domain	Min – Max Range	MEAN (obtained by 15 parents)	STANDARD DEVIATION
Social Interaction	4	4 - 28	19	4.864
Supervision	7	7 - 49	20	6.480
Caregiver Relief	9	9 - 63	27	7.741
Contentment	9	9 - 63	35	2.670
Safety	8	8 - 56	23	4.802
Technology Acceptance	9	9 - 63	50	9.04
Effort	8	8 - 56	26	5.316
Doing Activities	5	5 - 35	21	1.825
Autonomy	5	5 - 35	19	5.836

Table 4 shows the FIATS 9 domain score number of responses in percentage of parents (number of times) responding on 7-point Likert scale. The point scale responses were judged as strong, moderate and weak. Strong denotes positive influence and weak denotes poor influence. Scores were interpreted as strong if parents responded as 6 or 7, moderate for 4 or 5, and weak for 1, 2 and 3. Strong responses were more in percentage for the domains of social interaction, technology acceptance, doing activities and autonomy. Weak responses were more in percentage for the domains of supervision, caregiver relief, safety and effort.

Table 4: Likert Scale Responses Interpretation: FIATS 9 domain score Number of responses in percentage of parents

FIATS DOMAIN	STRONG RESPONSES (%)	MODERATE RESPONSES (%)	WEAK RESPONSES (%)
Social Interaction	54	16	30
Supervision	17	10	73
Caregiver Relief	24	14	62
Contentment	35	26	39
Safety	16	20	64
Technology Acceptance	64	29	7
Effort	21	12	67
Doing Activites	35	32	33
Autonomy	22	35	43

RESULTS

In the social interaction domain, parents' strong responses were 54%, moderate responses were 16% and weak responses were 30%, indicating improved interaction with the surroundings. Parents were happy that their child could interact, communicate and could join in family activities by using the seating device. Children reciprocated by watching people, television, etc. One mother reported the perceived benefit of the CP chair:

"He likes to be with us at mealtime; he is looking and listening to us. I can feed him and play with him more easily in the upright position. It enables me to face him instead of being behind him; he can learn and be more attentive to facial expressions."

In the technology acceptance domain, parents' strong responses were 64%, moderate responses were 29%, and weak responses were 7%, indicating high level of acceptance of technology. Parents believed that assistive technology would enable their child to learn activities of daily life. All the parents expressed satisfaction with the chair and said that it definitely helped in supporting their child to sit in an upright position. They found that the device was easy to handle by grandparents and siblings, and that the child maintained correct posture and participated in play more easily in the chair than when supported by a corner of the room, or by pillows or rolled-up bed sheets. The device lessened the strain on family members when lifting and carrying the child within the house.

Figure 2: Mean of the Nine Different Domains

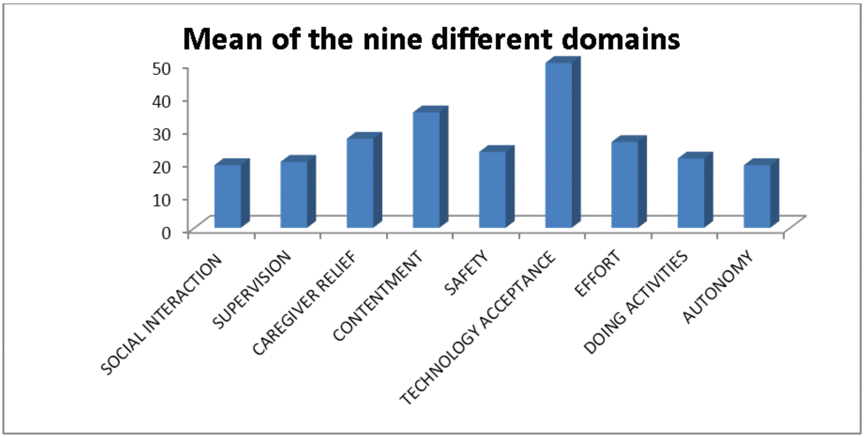
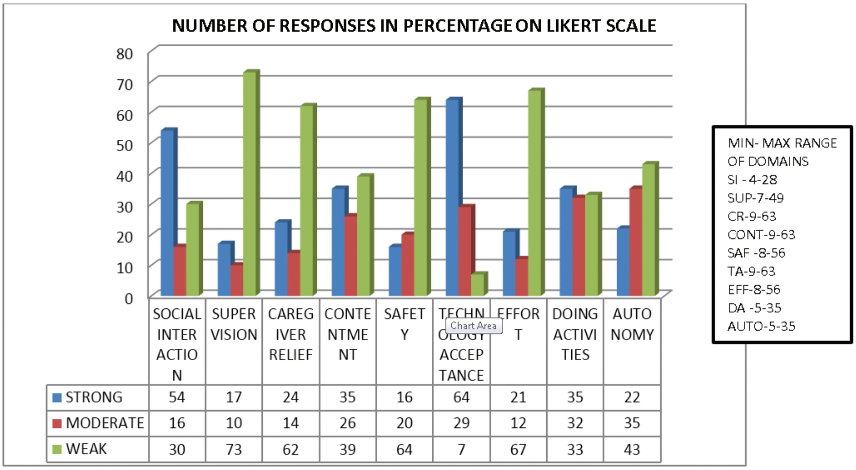


Figure 3: Parents' Responses in Percentage on Likert scale



	SOCIAL INTERACTION	SUPERVISION	CAREGIVER RELIEF	CONTENTMENT	SAFETY	TECHNOLOGY ACCEPTANCE	EFFORT	DOING ACTIVITIES	AUTONOMY
🟦 STRONG	54	17	24	35	16	64	21	35	22
🟥 MODERATE	16	10	14	26	20	29	12	32	35
🟩 WEAK	30	73	62	39	64	7	67	33	43

Acceptability of the chair was high, with all the parents indicating that it was easy to manage and that they use it consistently.

In the contentment domain, strong responses were 35%, moderate were 26% and weak were 39%, which suggest there was not much difference between strong and weak responses. In the doing activities domain, strong responses were 35%, moderate were 32% and weak responses were 33%. In the autonomy domain, strong responses were 22%, moderate responses were 35% and weak responses were 43%. When combined, the strong and moderate responses in the contentment, doing activities, and autonomy domains were more than the weak responses. Earlier studies have emphasized self-control over the environment as a goal in the management of children with cerebral palsy (Nwaobi, 1987). This study revealed that children were satisfied and were able to explore their surroundings. Parents were happy that their child's therapy was making progress. They also noticed positive changes in their child's happiness and ability to control and play with toys. Some parents reported that their child had more independence in the following ways:

"My child can explore his surrounding environment and he enjoys being able to do that. He does not have to pay attention so much on sitting up and can play with his siblings uninterrupted."

Interestingly, the seating devices seemed to have little effect on the extent to which parents needed a break from caregiving (caregiver relief), degree of energy needed to assist the child (effort), degree to which parents were worried about the child's safety (safety), and degree to which the child required attention from family members (supervision).

In the caregiver relief domain, parents' strong responses were 24%, moderate responses were 14% and weak responses were 62%, indicating very little relief from caregiving. Parents were unable to use the chair outside the house and preferred to carry their child to save the chair castors from damage. Also, they could not use the chair in other environments, for example when out shopping, and in banks, malls, theatres, public buildings, etc.

In the supervision domain, parents' strong responses were 17%, moderate responses were 10% and weak responses were 73%. They reported that they supervised their child more closely when the seating device was in use. They were worried that the child could fall if the straps were not secure. A few parents said that their child did not like to be strapped and constrained on the device and preferred to be mobile. Except for one ADL, i.e. eating, parents did not have relief from caregiving. Feeding was easier as the child sat comfortably in the correct position and the mother could also seat herself and feed the child without having to bend. Studies in the past have shown that adaptive seating devices are effective in improving some components of eating behavior (Nwaobi, 1987).

Parents had to devote a significant amount of time to activities of dressing, bathing, grooming, and toilet requirements of their child. Neither age nor level of GMFCS was a factor here. The child had to be lifted to go to the toilet as the chair has no attached facility. Again, it was not practical to bathe the seated child as water would damage the material of the CP chair, such as wood, iron fixtures, etc.

In the effort domain, parents' strong responses were 21%, moderate responses were 12% and weak responses were 67%. Parents reported that the use of the seating device had not made much difference to the amount of effort and energy needed to assist and handle the child.

DISCUSSION

A descriptive analysis of the FIATS questionnaire completed by parents revealed that the uninterrupted use of adaptive seating devices had an overall positive effect on the lives of families who have children with GMFCS levels III, IV and V as measured by FIATS.

The FIATS mean scores for children with GMFCS level IV were more on some domains as compared to children with GMFCS level V. The exploratory analysis of the mean subscale scores in this study points to interesting avenues for future research.

Parents were satisfied with the adaptive seating device that was provided as it was very durable, simple and easy to manage. They continued using the seating device for a longer duration as it had scope to accommodate the child's growth. Consistent use for 1 year or more was indicative of high acceptance of devices. These findings are supported by those of Washington et al (2002) who found that ease of use and comfort for their child were important factors affecting the usefulness of adaptive chairs for parents.

The maximum impact was observed in the extent to which children interacted with others socially (social interaction), the extent to which parents accepted assistive devices for their child (technology acceptance), the extent to which the child was content during the day (contentment), had control over his /her actions (doing activities), and could perform activities independently (autonomy). These findings corroborate those of Ryan et al (2009) who reported parent-perceived positive effect of adaptive seating devices on the lives of young children with CP.

All parents reported improvement in their child's functional skills such as play, hand use, and social interaction. This finding is supported by the study of Hulme et al (1987) who found behavioral and postural changes with use of adaptive seating by clients with multiple handicaps. In this study parents found seating devices useful over time.

The Hindi version of the FIATS scale, consisting of 64 items, was clear and easy to understand. Apart from the length of time needed to complete the questionnaire and some ambiguity in the questions of the safety and caregiver domains, not much difficulty was reported. This study helps in identifying the difficulties experienced by caretakers of children with cerebral palsy. While the use of a seating device definitely aids certain important areas of care, the existing system fails to meet the needs of bathing, toileting and transportation. Addressing these needs will provide relief for caregivers and will go a long way in rehabilitation of children with cerebral palsy.

Limitations

The current study is subject to number of limitations. The use of a convenience sample limits the application of the results. A restricted sample size within one region does not allow for widespread generalization of findings. The number of female caregivers was higher than male caregivers; the results might have differed on the overall impact of child and family life if more male caregivers had been examined. As more boys than girls with cerebral palsy were recruited, the findings were not compared on the basis of gender. According to GMFCS, levels IV and V were more prevalent than level III and could have influenced the study results. Participants' co-morbidities like intellectual disabilities, epilepsy, etc., were not compared as interaction with the environment from the upright position may also enhance psychosocial and cognitive development of the client. Since the work was done in a Government institute, there were constraints of time and other formalities. If the study could be replicated in other child rehabilitation centres in Mumbai, more data could be collected to enable generalization of the findings.

CONCLUSION

This study was a first step in gathering quantitative information on the long-term impact of seating device use among families of children with cerebral palsy who visit this rehabilitation centre. From the perspective of parents, FIATS is a measurement instrument that focusses on domains that give quantitative descriptions of seating devices used in the child's home environment. The study findings underline the importance and success of the long-term use of the Cerebral Palsy chair.

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