

RETHINKING THE BATHROOM FOR ADOLESCENTS WITH CEREBRAL PALSY: AN EXPLORATORY PILOT STUDY ADDRESSING PRIVACY AND INDEPENDENCE

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Abstract: Caring for a child with cerebral palsy (CP) at home represents a major challenge and can have a significant impact on the caregiver's physical and psychological well-being. Caregivers and professionals often feel uncomfortable with adolescents' emerging behaviours. Adolescents' need for privacy requires a certain level of independence to be achieved. However, the physical environment may cause problems in achieving the required degree of privacy. The main objective of this study was to explore and identify realistic, evidence-based solutions to promote independence and privacy in the bathroom for

teenagers with CP. The authors used a two-stage co-design process: the conception of the design solution, followed by validation. The results of this project demonstrate the need to combine original technical aids and environmental settings to create a safe, hygienic environment for the user. The results can guide therapists in their clinical approach to designing washing facilities that meet the hygiene and psychological needs of other adolescents, adults and seniors with mobility impairments.

Keywords: Cerebral palsy, adolescents, design solution, bathroom, independence, privacy.

Introduction

When children are young, caregiving is an important parental role. This role is often much greater when the child has permanent functional limitations that lead to long-term dependence. This can be the case when the child has cerebral palsy (CP), a non-progressive, permanent disorder resulting from damage to the developing brain (Ingram, 1964; Scoles, 1982) that occurs in 1.5 to 2.5 children per 1,000 live births (Murphy, Yedgin-Allsopp, Decoufle, & Drews, 1993; Oxford Register of Early Childhood Impairment, 1998). Along with motor impairments, many children with CP also have communication and cognitive impairments. Together, these can lead to complex limitations and restrictions on self-care activities. The task of caring for a child with CP with complex disabilities at home, therefore represents a major challenge and can have a significant impact on the caregiver's physical and psychological well-being. Although both the child and caregiver may show increased mastery of their respective skills and roles over time, the burden of care may also increase over time as both parties age.

Caring for a growing child with CP is an important consideration since 90% of children with CP survive into adulthood (Evans, Evans, & Alberman, 1990). Activities taking place in the bathroom are probably among the most physically demanding for children with CP with complex needs and their caregivers. Furthermore, contemporary society has rigorous hygiene standards, reinforced by

the media. It is commonly understood that a daily shower or bath and twice daily tooth brushing are required (Kira, 1976; Morales, 2007). Moreover, for many able-bodied individuals, their bathroom represents a private place for relaxation and self-indulgence (Morales, 2007). For people with disabilities, however, this same space, is often the scene of difficult and stressful experiences (Mullick, Preiser, & Ostroff, 2001), possibly due to a lack of accessibility and privacy. Thus, this qualitative pilot study had two main objectives:

1. To provide a sensitive portrait of the everyday struggles with basic hygiene activities faced by adolescents with CP.
 - a. To understand the solutions and procedures used by adolescents with CP and their caregivers when taking a shower.
 - b. To determine the independence and privacy needs of adolescents with CP when taking a shower.
 - c. To determine caregivers' needs in terms of assistance to the adolescent with CP in the shower.
2. To explore and suggest some potential solutions addressing the needs of this population.

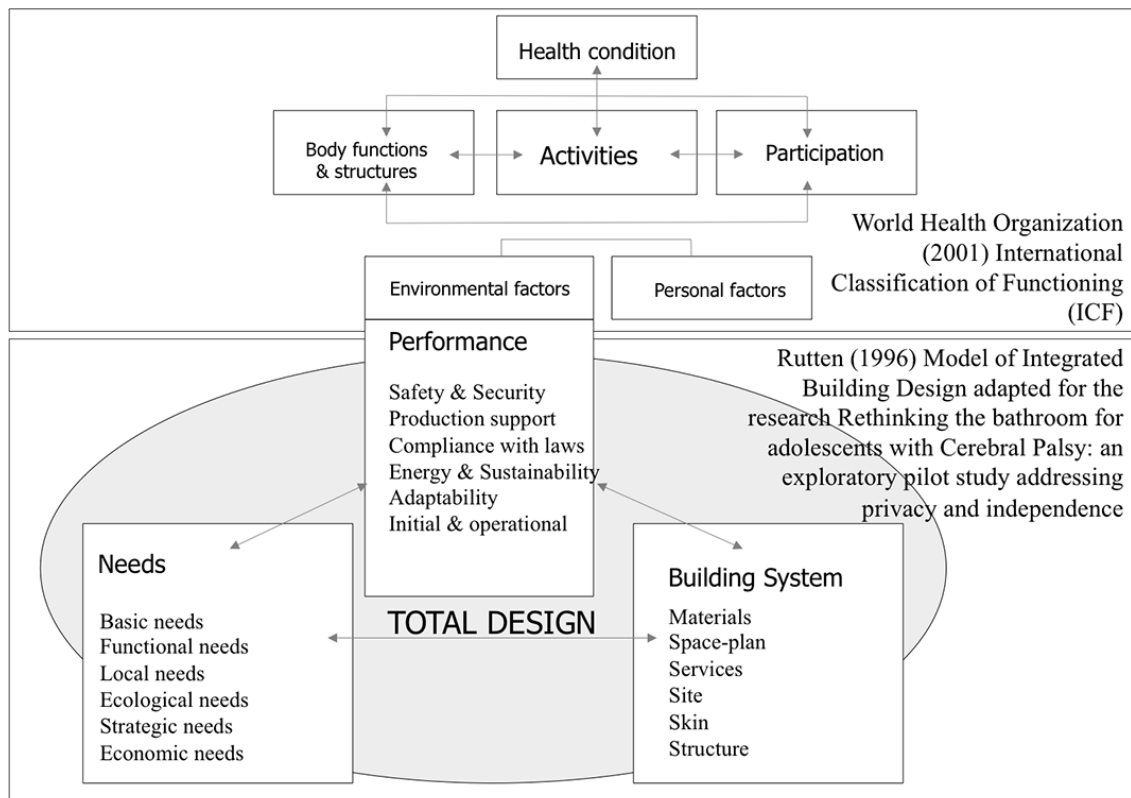
To address privacy and accessibility issues from a design perspective, the Model of Integrated Building Design (MIBD, see figure 1) (Rutten, 1996; Van Hoof, 2010) was particularly helpful. With this model, the relationship with accessible environments is viewed from different perspectives and is seen as a triangular relationship between (1) the needs, (2) the performance and (3) the design solution.

The usefulness of a design solution is related to its fit with the requirements of the stakeholders (in this case, adolescents with CP and their caregivers). For adolescents with CP who have complex needs, two bathroom requirements are likely: independence and privacy. Along with architectural barriers, dependence on caregivers for personal care is one of the main impediments preventing

adolescents with physical disabilities from developing independent social lives (Blum, Resnick, Nelson, & St. Germaine, 1991; Greydanus, Rimsza, & Newhouse, 2002; Nosek & Hughes, 2001). Although individualization and separation from one's caregivers are among the main goals of adolescence, caregivers may feel anxiety about allowing children with complex needs to take responsibility for themselves (Murphy & Young, 2005; Kewman, Warschausky, Engel, & Warzak, 1997). Privacy in the bathroom is particularly important to adolescents because physical growth and sexual maturation are prominent features of this developmental stage, and modesty is a natural response to these changes. For children with CP, adolescence begins earlier and ends later than in able-bodied children (Worley et al., 2002).

As for the other two factors in the MIBD, performance is the ability of the design solution to meet stakeholder expectations and needs. The design solution includes all elements relevant to the design process.

Figure 1. IFC/MIBD Model. Source: Rutten (1996); Van Hoof (2010)



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Methodology

The study used a qualitative co-design methodology (Ivey & Sanders, 2006; Sanders & Stappers, 2008; Sleeswijk Visser, et al., 2005), where the user or stakeholder is an “expert in his own experience” and contributes to the design of the solution. This study was divided into two main phases: the exploration of the current situation along with the conception of the design solution; and the validation of the design solution in consultation with experts.

Study participants

Three adolescents, three family members, and ten service providers (five occupational therapists and technician orthosis-prosthesis specialists, and five bathroom product specialists) participated. The inclusion criteria for the adolescents were: (1) having a diagnosis of CP; (2) being 13 to 21 years old; (3) using a wheelchair at all times for mobility; (4) being classified as level IV or V on the Gross Motor Function Classification System (GMFCS) (Palisano, Rosenbaum, Bartlett, & Livingston, 2008); (5) having sufficient cognitive and communication skills to permit active collaboration in the two study phases; and (6) using a standard or telephone shower at home. Family members had to be the primary caregiver at home of one of the adolescents, and service providers had to be experienced with the shower needs of young people with GMFCS level IV or V CP. All participants were clients, families or employees of Centre Intégré Universitaire de Santé et de Services Sociaux (CIUSSS) de la Capitale-Nationale, Institut de Réadaptation en Déficience Physique de Québec (IRDPO), with the exception of the bathroom product specialists, who were employed in private businesses in the community. The study was approved by the local institutional review board. With the exception of minors, written informed consent was given by all participants. For minors, this consent was provided by caregivers and the child consented to participate.

Protocol

Phase 1: Needs analysis and user-generated design solutions. The adolescents and their caregivers were visited in their homes twice. Meeting 1 was divided into two parts. Part 1 was a semi-structured interview with the adolescent and the caregiver to identify problems experienced in the shower. Sociodemographic and home adaptation information was also collected, including age; date of birth; number of people living in the house; number of bathrooms in the house; diagnosis; services received (what kind, from whom and specialty); and home adaptation (type, if there is one). To identify the difficulties, a series of questions were asked, such as:

- What experiences do you dislike most when you take a shower?
- What feelings and sensations are associated with taking a shower?
- How relevant to you is privacy in the shower?
- Do you think some bathroom activities require more privacy than others?
- If so, what are they?

The interview was digitally recorded. Part 2 involved making a video-recording of the adolescent having a shower in his/her own bathroom, wearing a bathing suit. This was done to provide the researchers and the service providers with (1) information on the procedures, needs, difficulties and possible solutions related to the shower; and (2) a visual and verbal description of the showering procedure from the adolescent's and the caregiver's perspective. At the end of the first visit, the adolescents and their caregivers were given a notebook, pencil and eraser. During the following week, they were to think about and record possible design solutions without regard to cost or development expense that would better allow the adolescent to take a shower independently, in private.

One week later, the second visit took place. The adolescents and their caregivers described their design solutions, while one of the researchers sketched the

solution on a large piece of paper so everyone could see the idea. This was particularly important since the drawing allowed all participants to provide relevant input. Following Phase 1, the research team finalized the preliminary design solutions based on the information from the two visits.

Phase 2: Validation (consultation with experts). Design proposals were criticized, enriched and validated by the participants during three focus groups. What is called “validation,” in this case, becomes a filter, a research strategy to “purify” and enhance the design and set some parameters for the unlimited process of creation in order to achieve more realistic, viable and sensible solutions. The main objective of this session was to assess and improve the design proposal from an adaptive and clinical point of view.

The three sessions followed the same co-design and brainstorming format: the two researchers (E.M. and D.M.) and the two clinicians (M-C. B. and C. P) explained the project in a PowerPoint presentation to the participants. A question period was allowed, and then the printed versions of the different design proposals on 60 x 90 cm sheets of paper were displayed so participants could suggest their ideas (modifications), These ideas were discussed to try to reach a consensus and then the main researcher drew them in on the printed diagram. Finally, the design solutions were modified according to the comments of the different focus groups: Group 1: adolescents (three individuals) and their caregivers (three individuals); Group 2: occupational therapists (five individuals); Group 3: bathroom product specialists (five individuals). Following Morgan’s (1988) recommendation, there were an odd number of participants in each group. All group sessions were digitally recorded.

Data analysis

The data were analyzed using content analysis (Mucchielli, 2009; Ryan & Bernard, 2000). Three of the co-authors independently identified the main concepts from Phase 1, Visit 1 that were directly related to design solutions. Concepts were then discussed and any differences were resolved through consensus. The graphic results from Phase 1, Visit 2 (drawn by E.M. and data from the participant

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notebooks) were then compared with the concept data (Ivey & Sanders, 2006). This process enabled the design proposals to be checked and filtered for validity.

Results

Needs of adolescents with CP

Need for independence

The teenage participants unanimously answered that genital hygiene is the task where they are most dependent on others, but where they would most like to be independent. Other tasks requiring assistance were washing their hair, back and feet.

"I can wash my face and upper body by myself but not my lower body."

Problems for the caregivers included inappropriate positioning (need to kneel on the floor next to the bathtub/shower to help with washing; need to transfer their child, etc.) that caused long-term back problems. Other elements such as splashing were also mentioned as being unpleasant.

"I have to be on my hands and knees to wash her... There is no curtain. We use the shower to rinse off, so both of us get wet."

Need for privacy

The adolescents unanimously mentioned that they would prefer to shower by themselves. However, they were used to having a caregiver perform this task, and it did not bother them. For example, one participant said that respect for privacy is desirable but not always realistic in this context. Another mentioned that the energy needed to be independent would likely result in fatigue. The third noted that having a non-family member caregiver is uncomfortable because that person will not perform tasks the same way a family member would. For example, the mother of one participant shaves her daughter's pubic area once a month.

"I could do it myself but I am used to always having someone there. It doesn't bother me."

"I have not had privacy for a long time. When it's my mother, it's better. When it's someone else, I have to get used to them."

Feelings regarding showering

What the adolescent participants valued most in taking a shower was an efficient way of getting clean and the feeling of warmth. Two of the participants preferred taking a shower instead of a bath for these reasons. One of the participants, however, especially enjoyed taking a bath, as it was warm and relaxing. Her caregiver agreed and added that she [OK?] could also take a break while her daughter was in the bathtub.

"What do you like most about taking a shower?" "It's quick. She likes relaxing in the bathtub, but there's never enough [hot] water. Since we installed the shower [with adaptations] it's quick; she's done in 15 minutes."

One participant used a ceiling-mounted mechanical lift from the bed to the bathroom. The rail stopped at the toilet so she could urinate before getting into the hot water. Keeping the room warm was a priority as the participant was sensitive to cold. After 20 to 30 minutes in the hot water, the water was drained to start the washing. Washing was done by the caregiver with a sponge, kneeling at the edge of the bathtub. The participant was rinsed with a telephone-type shower spout, dried, put back in the lift, and transferred back to her room where she was dressed in her bed. The main obstacles were a low bathtub and postural problems affecting the caregiver's back while soaping and rinsing.

"I like the older, lower tubs better because I have back problems. But our [modern] bathtub allows me to put more water in. The best thing to do is to be on my knees so I can be close. However, now I have help. You have the right to receive help, no matter how much money you make."

Another participant used a manual wheelchair to go from his bedroom to the bathroom. He then transferred from the wheelchair to the toilet to a wheeled

shower chair. The caregiver washed the participant from outside the shower and provided a towel for drying. Opening the shower curtain was minimized to keep the shower stall warm. The transfer process was then reversed after the shower. The main obstacles were the shower sill, the restricted space in the shower stall, the lack of a fixed temperature control and a soap holder that was inaccessible to the participant.

“The shower is relatively large, but still too small...because he has grown and his feet touch the bottom of the shower...it’s not easy to get the shower chair in. The shower has a little lip, you have to go over a little bump. We have no choice because of how the bathroom is built.”

The third participant was taken into the bathroom in her manual wheelchair. She performed a “sit-to-stand transfer” from the wheelchair to an adjustable-height (hydraulic) seat that was then used to transfer her into the bathtub. The main obstacles were a small space between the bathtub and the sink, the accessibility of the soap and the height of the bathtub.

“We made adaptations when we built [the house]. As she’s grown older, her needs have changed because of her condition...We added a lift...Sure, theoretically the bathroom could be a foot larger...we’ve realized that the counter is two inches too wide.”

Design proposals

Of the main problems identified, the lack of space was one of the most important. Regarding fixtures, the idea of a “car wash” shower with multiple shower heads was unanimously suggested. It was considered important to have a telephone-type shower head and another fixed shower head that could be directed at the adolescent, to provide a continuous flow of warm water, as well as other shower heads at specific locations that could spray water or soap. Control of water intensity and temperature by a button-type “interface” or a joystick was also suggested.

During Phase 1, Visit 2, each adolescent and caregiver provided ideas related to design solutions. These solutions were then presented to the three focus groups (Phase 2). The three design solutions judged the most relevant by the research team and the experts are presented here.

Shower chair

The shower chair should have a toilet seat-type opening and bidet-type fixtures. There should also be water jets in the back and legs of the chair (see figure 2).

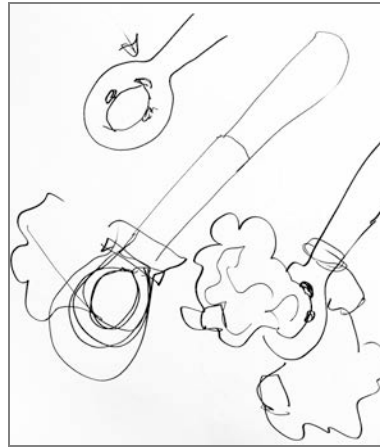
Figure 2. Shower chair. Source: Authors.



Extensions

Extensions that attach to water or water/soap jet with a soft sponge-like material at the end would be desirable, especially if operated with an infrared system (see figure 3).

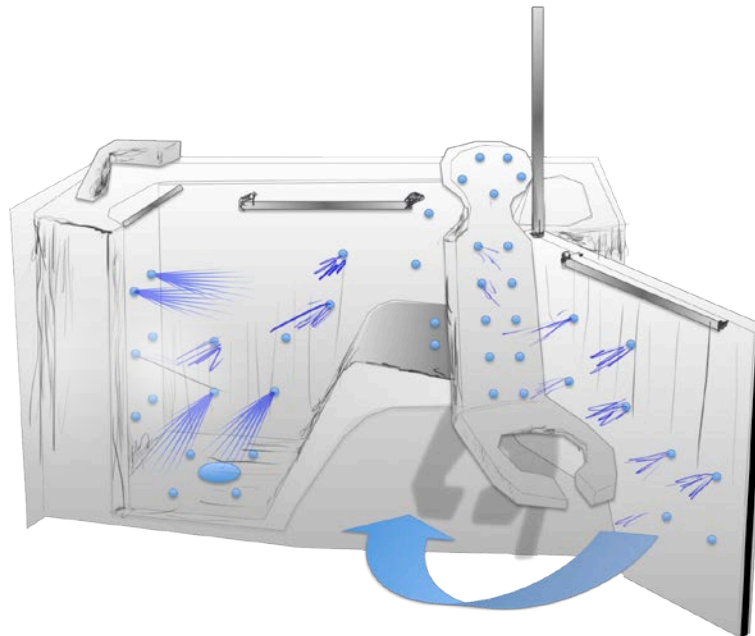
Figure 3. Sketch of extensions.



Shower-bath

A walk-in bathtub with a bath chair on wheels that could be anchored to the bathtub door would facilitate transfers. The bathtub should have water jets in its walls and base so it could be used for a bath or shower. The jets could also facilitate rinsing the perianal area—through the above-mentioned opening in the bath chair. This jet system would also allow the person to stay warm while in the tub (see figure 4).

Figure 4. Shower-Bath.



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Discussion

Need for independence

The adolescents and caregivers in this study were aware of each teenager's abilities and limits in the shower and bathtub and of the considerable amount of energy that would be required by both the adolescent and the caregiver to support full independence. Independence in the shower or bathtub was therefore not a priority for either group. Furthermore, the participants recognized that they were never likely to be able to wash their hair or genitals without help. However, the results also showed that the amount of caregiver assistance provided was sometimes more than was required, which constituted a barrier preventing the teens from becoming more independent, even if full independence was not realistic. The provision of more assistance than was needed may have been related to time constraints and hygiene standards (Kira, 1976).

Need for privacy

All three adolescent participants said they would prefer to be able to manage their hygiene without personal assistance. However, they also agreed that this was unrealistic given their limitations. While they reported being used to receiving the help of a caregiver, they preferred someone they were familiar with, whom they could trust, whether this was a family member or not. All of them also expressed a greater need for privacy when they had many caregivers or a new caregiver.

Performance

Although the three adolescents' homes had been evaluated and adapted under the supervision of an occupational therapist specializing in home adaptation, some areas of need still remained. For example, the teenage participants and the

caregivers suggested larger bathrooms and shower spaces and more accessible shower and bathtub fixtures.

Design solutions

Given the diversity of limitations and environmental contexts, one design solution cannot meet all needs. However, the adolescent participants and their caregivers agreed that a combination of design solutions would likely increase their independence in dealing with personal hygiene even though some assistance would always be required. For example, it was unanimously felt that the heat provided by water jets would have a relaxing effect. This was considered beneficial, as spasticity and related discomfort or difficulty with positioning can temporarily increase during bathing or showering if the person feels cold. An opening in the shower seat that would allow access to the perianal area and use of the toilet before showering or bathing was also suggested as a solution. However, it was recognized that this type of chair would be technically complex to design. Another unanimously accepted design solution to increase independence was extensions. Given the upper limb motor limitations of the participants with CP, however, additional work is required to develop a handle that would allow them to control the extensions. The extensions would need to be made from a material that was safe, washable and hygienic.

The shower-bath solution would meet the need for relaxation, maintain a warm temperature and prevent caregivers from getting soaked. However, since the shower-bath should be level with the floor so the chair can get in, the caregiver's position could be problematic. Participants liked this solution because it would allow the adolescent to stay warm and because of the additional water jets for the perianal area. This design solution could be used by any member of the family; it would help seniors with their hygiene practices, and it would occupy the same area as a regular bathtub.

The combination of the extensions with the shower chair or the shower-bath might give adolescents with CP greater autonomy.

Study limitations

The results of this study are limited to adolescents with CP who use a wheelchair for mobility and their caregivers. It is likely, however, that at least some of these results will apply to other populations with similar needs, such as adolescents with a neuromuscular condition or adults with CP at GMFCS levels IV and V. Another limitation was the small sample size (3 adolescents and their caregivers). A small sample size was chosen because of the co-design methodology, which requires one to go “deeper” rather than wider with data collection. Greater breadth of results came from the service providers in Phase 2 of the study.

Conclusion

Using the MIBD, this qualitative study aimed to explore problems and solutions affecting bathroom design for adolescents with CP with complex care needs. The results highlight the need to explore new and existing technical aids in the bathroom environment to facilitate showering. While all adolescent participants expressed a desire to be more autonomous in achieving their personal care, motor disabilities limit their independence. Therefore, human assistance remains necessary, which affects their privacy. This seems, however, to be tolerated by the teenage participants. Caregiver involvement is necessary, but the level of aid provided is sometimes greater than required, increasing the burden of care.

It is suggested that needs for independence and privacy should be evaluated as part of clinicians’ intervention process in the bathroom area. This would allow a better match between needs and proposed solutions in order to optimize the performance of the tasks. In addition, it is recommended that occupational therapists educate caregivers about the risk of injuries related to showering, so they can design a bathroom while their children are young that will accommodate their future growth. This would contribute to allowing teenagers with CP to stay at home and avoid institutionalization. In this regard, it would be interesting to document the impact on caregivers of the introduction of design solutions meant to promote independence for a child with CP at the early stages of life.

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Considering the data collected and the concrete identification of design solutions, future research will focus on testing the prototypes. If the prototypes prove to be effective, the training of occupational therapists in the use of this equipment will be essential so adolescents with CP can gain more independence and privacy.

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