FAMILY-BASED TOILET TRAINING PROGRAM FOR CHILDREN WITH MILD CEREBRAL PALSY TYPE DIPLEGIA

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Abstract

This research aims to design a family-based toilet training program for children with mild cerebral palsy, diplegic type. The research method used is a case study with a qualitative approach. The subjects of this research were HW, an 8-year-old child with cerebral palsy, and her family. Data collection was carried out by interviewing parents and observing parent and child activities related to toilet training as well as toileting ability tests carried out on a child to clarify the data found. Based on the results, it was found that the parents had carried out toilet training activities but HW was still unable to do it because there were several obstacles including the motor aspect where the child was not being able to squat. Based on these problems, a program was created for parents to teach their children using task analysis and continuous training using portable toilets for children. This program specifically emphasizes several aspects, namely parental knowledge, physical readiness, intellectual and psychological readiness

Keywords: toilet training. family, cerebral palsy

INTRODUCTION

Cerebral palsy (CP) is a condition of permanent impairment in motor development and posture, which can cause limitations in activities and can be associated with non-progressive disorders that occur during the development or maturation process of the infant's brain (Supriyanti & Prihati, 2023). CP can be considered as the most frequent childhood motor physical disorder. CP is caused by brain injury or impairment and may occur during the prenatal, perinatal, or postnatal period. The severity and type of impairment depend on the size, type, and location of the brain injury. Motor movements and posture are the areas most affected by this disorder (Guimarães et al., 2023).

Cerebral palsy has different levels, ranging from mild, moderate, and severe or requiring the assistance of others completely (Pursitasari & Allenidekania, 2019). Children with CP are prone to self-care limitations and require special assistance to fulfill their needs. Moreover, CP is a lifelong disorder that often results in long-term dependence on parents, which forces them to assume different roles and face additional challenges and needs (Guimarães et al., 2023). However, children with cerebral palsy can still be optimized for their developmental abilities.

Toilet training skills for children with cerebral palsy are of course very different from children in general, both in terms of their abilities and in terms of the time needed to complete activities in the

toilet. Toilet training ability is one of the developmental tasks of children at toddler age or age 1 - 3 years. The ability that each child has in toilet training varies depending on the development during the toddler period that has been achieved by the child (Khair et al., 2022). Toddler age or age 12 - 36 months children experience three phases, namely the autonomy phase where children can take the initiative and do it themselves, reject something, and try something that the child want. In the anal phase where children enter the toilet training period and the preoperational phase where children can make judgments about objects and events around them, it can be concluded that in the second phase or anal phase children can carry out toilet training (Khoiruzzadi & Fajriyah, 2019).

Parents are a figure that is needed by children, be it parents as examples in daily activities, parents as mentors and educators for children, so the role of parents is very dominant in the family. In addition, children can spend a long time at home with their parents, so parents should provide learning for children in various ways. According to (Yasmin et al., 2023) family is a system consisting of several sub-units, namely father, mother, and children if the family is a family.

Parenting patterns can be influenced by family ecology. In this case, the family can play an important role in the development of children, especially children with special needs. Children can also confidently optimize their abilities if the environment where the child is located supports the child to continue to develop (Yasmin et al., 2023). Parent participation and involvement is an important components in their child's development intervention (Phoenix et al., 2019) because parents or families have a lot of time to be with their children. Establishing and maintaining parental involvement needs to be done in a directed and meaningful way so that the child's potential can continue to be developed (Sari, 2020). Parental involvement in CP interventions provides hope for the child's progress and development (Harniess et al., 2022).

Field studies have identified a case of an 8-year-old child with cerebral palsy, type diplegia, namely HW, who experiences movement difficulties in the lower limbs. The child's legs become stiff when bent and tiptoe when walking. These limitations make it challenging for the subject to use the toilet for defecation and urination. Considering various factors, including the child's age, which has entered elementary school, it is hoped that the child can express and carry out their wishes regarding urination and defecation at school and home. Additionally, parents are struggling to find effective solutions for toilet training. Currently, parents still use children's underwear if the child wants to defecate and invite the child to the toilet if they urinate, but in a standing position. From a hygiene perspective, this approach is not ideal for the child's health or the cleanliness of the home, as the child also cannot remain quiet during defecation. This situation has become a source of complaint and anxiety for parents, who are seeking a solution to enable their child to independently manage defecation and urination activities.

Based on the challenges faced by HW and his family, specifically the difficulty in toilet training for HW, who has cerebral palsy type diplegia, resulting in the child being limited in the toilet, a program is needed that can facilitate the child and guide them in toilet training activities. Additionally, it is essential to involve parents and other family members, including the older sister, in training the subject to perform toilet training. This program is crucial for the child because as the child grows older, their developmental tasks will also increase, and it is the responsibility of those around them to intervene in toileting activities. Furthermore, parents also have the potential to intervene for the child.

METHODS

The study employed a qualitative case study approach. Data collection will be limited by activities and time, as well as comprehensive data collection procedures with a predetermined timeline. The study involved a subject, an 8-year-old child with cerebral palsy (HW), and his 43-year-old mother.

The study was conducted in three stages: stage one, stage two, and stage three. Stage one involved data collection through interviews with the child's mother, observations, and toileting skill assessments. Stage two involved analyzing the data from the interviews, observations, and assessments. Stage three involved developing a program based on the analysis of data from the previous stages. After the program was developed, it was validated through expert judgment with experts and practitioners in special education.

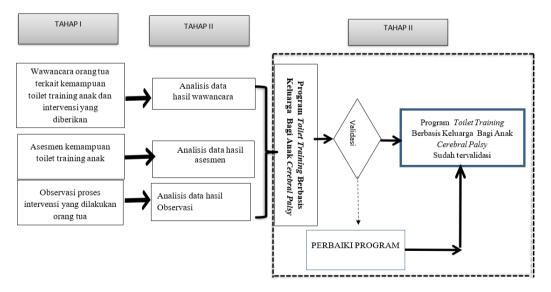


Figure 1. Research flow

RESULT AND DISCUSSION

The subject, HW, is an 8-year-old child with mild cerebral palsy, type diplegia. HW experiences stiffness in the lower limbs, particularly in the legs, which causes the child to walk on tiptoes and experience pain when bent or squatted. The results of the Denver II Test indicate that HW's abilities are delayed or not meeting expected developmental milestones, particularly in the areas of personal social skills, fine motor skills, and gross motor skills. At the age of 2 years or 24 months, HW's social skills are not yet developed to the point where the child can dress independently, but the child can take off clothing independently. In terms of fine motor skills, HW's hand stiffness prevents the child from using a pencil properly, as indicated by the child's inability to draw a vertical line. In terms of gross motor skills, HW has limitations in balance, which affects the child's ability to jump. For jumping activities, HW tends to hold onto objects around them.

The limitations of the subject, HW, were also confirmed through interviews with the parents. The parents were unaware of the exact cause of the limitations, but during the pregnancy, the mother experienced coughing from the 4th month of pregnancy until childbirth. However, this was consulted with the local midwife, who stated that this is a common occurrence in pregnant women. The parents noticed something different about their child when the child was 4 years old. At that time, the parents realized that their child could only say one or two words, such as "mama" and "papa." Physically, HW walked on tiptoes. After discovering this, the parents sought massage therapy in Cicalengka and received a diagnosis that HW had stiffness in the muscles of their legs. Due to time and distance constraints, the parents chose an alternative therapy, opting for occupational therapy, speech therapy, and physical therapy at RSUD Al-Ihsan, which was conducted twice a week.

In terms of gross motor skills, the subject was able to walk independently, although their legs were still stiff. When walking on uneven terrain or climbing stairs, the child tended to seek out objects or people to help them. For jumping activities, standing on one foot, and squatting, the child was unable to perform these activities due to the stiffness in their legs, which caused pain when bent.

In terms of fine motor skills, the subject was able to follow instructions to pick up and hold objects but was unable to perform activities independently due to the slight stiffness in their hands. The child was also able to lift certain objects, such as a half-filled cup, but needed guidance on how to hold it properly. In terms of personal social skills, the subject was able to perform activities such as drinking from a cup, eating with a spoon, and opening their clothing. However, the child was unable to dress independently and needed assistance from others. The child was also unable to fasten and unfasten their clothing independently.

In terms of language development, the subject was able to identify parts of their body, name colors, and animals, and count. The child also understood what others were saying to them and tended

to speak and ask questions frequently. It can be concluded that the child's language development improved before and after speech therapy.

In terms of toileting activities, the subject was unable to perform these activities independently. The child used their underwear for bowel movements and performed urination activities in the toilet while standing. The child was unable to squat due to the stiffness in their legs and felt uncomfortable when their underwear was wet or when objects interfered with their activities.

The acceptance and views of HW's extended family regarding his condition are quite positive. This is partly because HW's paternal uncle also has a child with certain disabilities, which has led to HW being well-accepted within the extended family. However, some family members have suggested that HW should be able to manage bowel and bladder control independently by the age of 10. They believe this will not be achievable without proper training and education for the child. In the home environment, HW is also well-accepted. The surrounding community actively helps to ensure HW's safety, particularly when he goes out without informing his parents. This supportive environment contributes to HW's potential for development, as the community does not discriminate against him based on his condition. The family's economic support is also considered adequate. HW's father is the primary breadwinner, currently working to provide for the family. All daily needs are being met satisfactorily. HW's older sibling is still attending junior high school, and his mother is not currently employed. The parents have hopes for their child's condition, wishing for HW to become more independent in daily activities and to manage his emotions effectively. They hope that he will refrain from disruptive behaviors, such as pulling or hitting his older sibling, which would improve the relationship between HW and other family members. HW has a strong bond with his mother, which makes him closer to her; however, he tends to be more compliant with his father's instructions. He is somewhat spoiled and often resists tasks when asked by his mother.

The development of a family-based toilet training program for children with mild cerebral palsy, type diplegia, involves the following steps:

a. An analysis process based on findings in the field. In this study, the results of the exploration that have been carried out are assessments conducted on children with special needs, as well as on the families of children with special needs conducted on the subject's mother regarding toilet training activities. The results of the assessment produce a profile related to the abilities, needs, and obstacles experienced by children and parents when carrying out toilet training activities. The results of the assessment will produce implications for needs and those related to family-based toilet training development programs.

- b. After analyzing the results of interview and observation data, a literature review is carried out that supports the results of the exploration found and it is also used as a basis for making and supporting program design.
- c. The program formulation is made according to the results of the analysis of interview and observation data which emphasizes several aspects, namely parental knowledge, physical readiness, intellectual readiness, and psychological readiness.
- d. After formulating the program through the planned program grid and outlining it in the form of a Guidebook for the Development of a Family-Based Toilet Training Program for Mild Cerebral Palsy Type Diplegia Children. The formulation of the program is obtained from the analysis of empirical studies and literature reviews so that the material provided is tailored to the needs of the subject and existing theory.
- e. After the program is made, the next program is validated by experts in their fields. The experts who became validators consisted of three people consisting of one UPI Special Education lecturer, the Principal of SLB G YBMU Baleendah, Class teacher.

Table 1 Design of Family-Based Toilet Training Program for Children with Cerebral Palsy

Aspects: Physical Motor Development, Barriers and Handling								
Time : 2 x 45 minutes								
Objective	Indicator	Materi	Activities	Methods	Media	Evaluation		
Understan ding physical and motor developme nt	Parents and other family members can understand physical and motor development	Milestone development	1. Introducti on 2. Appercepti on of physical and motor	Lecture, discussi on	a.Material book for the developme nt of a family- based	Practice questions and skills		
Understan d the barriers that children have according to their developme ntal age	in children Parents and other family members can understand and recognize their child's barriers.	Profile related to the assessment that has been conducted	developmen t 3. Presentati on of physical and motor developmen t materials	Lecture, discussi on	toilet training program for children with cerebral palsy- type diplegia, b.Pants,	Practice questions and skills		

Understan d and perform self- developme nt activity skills	Parents and other family members can provide interventions related to development al aspects that support toilet training.	Activities that support toilet training: 1.Buttoning 2.Zippering 3.Wearing clothes (pants) 4.Positioni ng the dipper	 5. 7. 8. 	discussion and question and answer	Demonstr ation, drill, and task analysis	c.Buttoning and zippering media, d.Dipper	Task analysis of interventi on implementa tion for activities toilet training support activities
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Aspect: Independence (Toilet Training)

Time : 2 x 45 minutes

Objective	Indicator	Materi	Activities	Methods	Media	Evaluation
Understan	Parents and	Toilet	1.Introductio	Lecture,	a. Family-	Practice
ding	other family	training	n	discussi	based	questions
concepts	members	concept for	2.Toilet	on	toilet	and skills
and	understand	cerebral	training		training	
skills of	the concepts	palsy	apperceptio			
toilet	of toilet		n		program	
training	training for		3.Presentatio		developme	
for	children		n of toilet		nt	
children	with		training		materials	
with	cerebral		concepts			

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cerebral	palsy.		4.Conducting		for	
palsy			discussion		children	
Able to conduct family-based toilet training activitie s	Parents and other family members can implement family-based toilet training activities.	Toilet training activities	and question and answer 5.Conducting demonstrati ons of toilet training activities 6.Evaluation 7.Closure	Demonstr ation, drill, and task analysis	with cerebral palsy, type diplegia b. Toilet training aids (sitting	Task analysis of toilet training interventi on implementa tion
			7.Closure		toilet)	

The delayed development in HW can be attributed to the suboptimal interventions and delayed handling by the parents of the subject's condition. The early years of a child, often referred to as the "golden age," are crucial and serve as the foundation for future development. During this period, children have the greatest potential for rapid growth. If this period is not optimized well and maximally, it will affect their future life and hinder further development. This aligns with the view that the golden age cannot be repeated and only occurs once, therefore, parents need to optimize and maximize their child's development during this period (Rijkiyani et al., 2022). Another perspective states that children in early childhood, aged 0-8 years, are children who grow and develop within their family or environment, which has a strong influence on their lives.

Children with cerebral palsy, who experience stiffness in their limbs, will face significant challenges in terms of mobility and Activity Daily Living (ADL). This underscores the importance of developing ADL skills, including toilet training (Heryati et al., 2023). Similarly, in the case of HW, the child has a significant delay in development compared to their current age. This condition is due to the lack of handling by the parents, who only realized that there was something different about the child when the child was 4 years old. However, this does not become a problem for starting over and optimizing the child's abilities at this time. The parent's decision to involve the child in therapy activities has shown that there is intervention being carried out, which will enable the child to catch up in future development. In terms of language development at the age of 4, it was found that the child was unable to communicate effectively, only being able to utter one to two words. However, after the child underwent speech therapy, the child was able to communicate and is now known for being talkative and tends not to be quiet.

Based on the objective assessment of HW's condition, it is clear that the child requires a program for toilet training that can support their current physical condition. Children with cerebral palsy tend

to achieve bladder control at a later age compared to typically developing children (Saleem et al., 2022). The most effective way to teach this skill to children is through demonstration, where they can observe others performing the task and then imitate it. This approach is also closely tied to the analysis of tasks designed in detail to ensure the child can perform them correctly.

Parental support in the education and potential development of children with special needs is very important (Rendani & Fatmawati, 2021). Parents and other family members have the potential to teach children because they have more time at home. In addition to the toilet training program designed for children, there is also something to focus on for children, namely optimizing and training their fine motor skills related to lifting the dipper, buttoning or zipping their skirt or pants, and wearing their clothes. In the formulation of program development, discussions were also held with special education experts consisting of lecturers and special education teachers. And for the implementation of the program, of course, is carried out by parents and other family members and there is also a guidebook that will be given to parents.

Parental knowledge regarding the condition of their child, due to interactions and communication with other parents during therapy and with experts in the field, is crucial. Good parental knowledge about the limitations of cerebral palsy will help reduce the risk of the existing disorder worsening (Forthun et al., 2020). Currently, parents and the family understand more about the child's development and are further optimizing the child's abilities. The child is no longer undergoing therapy because they have been categorized as having completed their previous therapy. The family environment is the closest environment to the child, often referred to as the microsystem. According to the findings from the field, the attitude shown by parents is at the acceptance stage because parents have begun to recognize, understand, and start solving the problems their child is facing. The environment where the child lives is also said to accept the child well, according to Hurlock. This is a factor of self-acceptance, where the extended family is the main source of strength and parents have a place to share, gain motivation, and not feel alone.

The extended family plays a significant role in encouraging parents to accept their children, but in practice, some beliefs suggest children with special needs can independently manage bowel and bladder control by the age of 10. However, this is challenging if not trained early. This aligns with the toddler stage, where children experience three phases: the autonomous phase, where they can take initiative and perform activities independently, but more often show their desires by rejecting what they do not want and trying what they do want. The second phase is the toilet training stage, and the third phase is the preoperational stage, where children begin to make simple evaluations of objects and events around them (Khair et al., 2022; Khoiruzzadi & Fajriyah, 2019).

The ability to control and schedule toilet use in children with cerebral palsy can be considered one of the most important self-care skills. Often, independence in toileting also determines acceptance in school. It is recommended that toilet training start early and that children should be trained to use the toilet by the age of 5 to 6 years before entering the school system (Zhagan, 2023). Children and adolescents with cerebral palsy face unique challenges when learning, practicing, and mastering daily life activities (ADL). Active participation in using the toilet is one of the activities that often poses a challenge for them (Kalisperis et al., 2020).

Toilet training during the toddler stage is an effort to train children to control their desire to urinate and defecate. Independence must be trained and developed in children as early as possible to avoid hindering their future development (Khair et al., 2022; Zhagan, 2023). If we look at the opinion of the extended family that children can independently manage toilet training, this is not in line with theory because if parents wait without conducting any intervention or special training for the child, the child will experience regression that is not in line with their age and the developmental stage will not be achieved. When parents provide training to children regarding toilet training, consider the child's readiness in terms of physical, intellectual, and psychological aspects.

Another factor supporting the acceptance of children by families is the economic factor. The family has a father who works to provide for the family and a mother who is a homemaker, taking care of the family at home. From this economic factor, parents can meet their living needs well and provide facilities for their child to develop their abilities. If we look at daily activities, where parents can involve their child in recognizing new things for the child, the parenting style adopted by parents is a democratic style, where parents can guide their child rationally, be open-minded, and teach their child to live independently. This style can create a balance between the rights and responsibilities of parents and children, so they can be accountable for their actions.

There are six actions in democratic parenting: first, rational and responsible behavior; second, open and thoughtful behavior; third, objective and firm behavior; fourth, warm and understanding behavior; fifth, realistic and flexible behavior; and sixth, fostering self-confidence and self-belief (Pratiwi, 2020). This is demonstrated by parents being open with their children and giving them opportunities to develop themselves, the father being strict and making the child follow his instructions, and the activities given to the child being tailored to the child's current age. The family is the closest source to the child, so parents strive to develop the child's abilities as much as possible.

After the profile of the child and parents was found, a family-based toilet training program was designed for children with mild cerebral palsy, type diplegia. Information about toilet training is important because toilet training is a crucial phase in a child's development, and almost all parents will be involved and participate in toilet training (Van Aggelpoel et al., 2019). The validated program

is intended for parents and children to carry out toilet training. The development of this toilet training program includes supporting materials for toilet training activities and activities for bowel movements and urination, which can train the child's independence in terms of personal hygiene. Based on the results of the program validation, the program can be implemented according to the validated program.

Independence in daily activities, including toileting, will help reduce the child's dependence on others. Additionally, it will be one of the factors influencing the improvement of the child's quality of life and independence in adulthood (Alvandi et al., 2023). The independent toilet training program that can be implemented is one of the learnings that can be further developed by the family or parents.

CONCLUSIONS AND RECOMMENDATIONS

Based on the research findings, it can be concluded that the family-based toilet training program for children with mild cerebral palsy, type diplegia, is a program that can help families with bowel and bladder control activities in the toilet. The development of toilet training provided includes detailed program analysis, as well as activities that support the implementation of toilet training, such as reusing clothing, using zippers or buttons, and practicing cup handling. The development of the program is based on the results of field analysis and is tailored to the child's abilities, limitations, and needs.

Toilet training activities have been carried out by families for children with cerebral palsy. Parents communicate with their children regarding bowel and bladder control, as well as the use of diapers or pants when they need to urinate. When the child feels the need to urinate, they will express it, but they do not want to go to the toilet. Parents have already invited the child to the toilet, but the child tends to cry and resist going to the toilet to urinate. Instead, the child prefers to urinate outside the toilet. In contrast, the child performs urination in the toilet while standing. This is due to the child's stiff legs and the child's pain when their legs are bent.

This toilet training program can be a solution in developing the ability of CP children to perform daily activities, so it is hoped that it can help parents in training their children who experience motoric limitations. This family-based program will be closer and more realistic to implement because it is based on the analysis of the child's and family's needs.

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