

Caretakers' Role in Personal Hygiene Children with Down Syndrome

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ABSTRACT

Background: Despite their flaws, children with down syndrome require caretakers' involvement, especially in personal hygiene. Caretakers play a critical role in meetings in terms of cleanliness. This study investigates the role of caretakers in the Personal Hygiene of children with down syndrome.

Subjects and Method: This study was a qualitative phenomenological approach conducted at Public Disability-Specific Schools in Semarang, Central Java, Indonesia. Purposive sampling of 10 people based on specific criteria is used to find participants. In-depth interviews, observations, and field notes were used to collect data.

Results: This study has resulted that the role of caretakers in the personal hygiene of children with down syndrome is divided into five themes: developing communication skills with children, providing examples through specific media, providing surrounding support, providing a reward or consequences, and modeling.

Conclusion: The role of caretakers has a significant impact on the learning of personal hygiene, so strategies are required to enable children to carry out self-cleaning tasks thoroughly.

Keywords: caretaker; personal hygiene; down syndrome.

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BACKGROUND

Down syndrome is a condition characterized by chromosomal genetic abnormalities caused by trisomy 21 (21), in which a person typically has 23 pairs of chromosomes from both parents or 46 chromosomes. People with down syndrome, on the other hand, have 47 chromosomes and are frequently found to have health complications

and poor mental and physical development (Shimada, 2021).

The WHO estimates that there are 8 million individuals with down syndrome worldwide. With an estimated incidence of 1 in 1,000 births, it affects between 3,000 and 5,000 babies born around the world. According to a health study (riskesdas), more Indonesians with down syndrome were diagnosed between 2010 and 2018.

Children between the ages of 24-59 months had a 0.12% prevalence of down syndrome in 2010, which rose to 0.13% in 2013 and 0.21% in 2018. Additionally, riskesdas 2018 notes that down syndrome is the disability type that most significantly contributes to disability overall, comprising 0.21% of the total population of 57,361 people (Ministry of Health, 2019).

Children with down syndrome experience a delay in cognitive development, according to Tuomo Matta et al. in Yuko Yamauchi et al. (2019) Typically, their IQ shows mild to severe mental retardation. Between the ages of six months and two years, children with down syndrome exhibit delays in cognitive development. Cognitive abilities in children with down syndrome are not those of typical children. Rather than improving compared to children their age, their cognitive abilities will deteriorate (National Center on Birth Defects and Developmental Disabilities, 2022). Children with down syndrome and typically developing kids both strive to be independent. However, children with down syndrome grow more slowly compared to other kids (Rina, 2016). Treatment is therefore required to assist children with Down syndrome in becoming independent. Another study found that children with Down syndrome have a physical dependence, even those with trouble caring for themselves or maintaining their personal hygiene. According to research on the level of dependency in kids with Down syndrome, the student will also exhibit total dependence (Aryanti, 2020).

Children do not naturally possess wisdom, morals, or virtues. These characteristics contribute to the child's identity and personality, giving each child a distinctive identity that sets them apart from other kids. All of these abilities have in common that they are first learned, honed, and developed at home, including in children with

down syndrome (Backović et al., 2021). The belief that people with Down syndrome are perpetual children leads to a lack of concern for identifying them at other life stages, as well as a lack of commitment from professionals and family or caretakers to recognize that they will go through puberty, adulthood, and old age, and will have intrinsic needs at each stage, regardless of their condition (Miranda et al., 2015).

Children with down syndrome require health care focused on maintaining their way of life, including personal hygiene and self-care. Concern for cleanliness and caretaker becomes a crucial pillar of independence and planning (Farias et al., 2020) Personal hygiene is an absolute necessity for all humans. Personal hygiene is a self-care practice that helps to maintain one's health. Personal hygiene is maintained for the individual's comfort, safety, and health. Personal hygiene is essential for reducing exposure to environmental diseases (Chairil and Hardiana, 2017). Children with special needs, including those with Down syndrome, have a more difficult time developing healthy hygiene habits because they lack the necessary skills and are hypersensitive to the stimuli associated with these tasks. Physical limitations, behavioral issues, and other factors in personal hygiene make it challenging to maintain personal hygiene practices (Hidayati et al., 2019).

To improve the quality of life and enable independent living for children with down syndrome, parents' crucial role in raising and educating children is to create an environment conducive to and supporting children's growth and development (Marta, 2017). Children with down syndrome develop in the same way as typical children in addressing daily needs. Personal grooming is one way to enhance the life of a child with down syndrome. Due to their physical, mental, social, and emotional limitations or

specialization in necessary developmental fields, their reactions to stimuli do, however, differ slightly (Ministry of Women's Empowerment and Child Protection, 2013). Based on the phenomenon, researchers want to investigate the role of caregivers in the grooming of children with down syndrome.

SUBJECTS AND METHOD

1. Study Design

This is a qualitative research project that takes a phenomenological approach (Creswell and Poth, 2016). Throughout several meetings, data was gathered through in-depth interviews and observations at SLB Negeri Semarang and the participants' homes.

2. Population and Sample

Purposive sampling was used by researchers who adhered to the inclusion criteria established by the researchers, such as being direct caretakers, caring for babies up to the present, and living in the same house. In contrast, teachers of students with down syndrome only spoke with triangulation participants once.

Researchers conducted in-depth interviews and observed participants to collect data. There are 10 participants. Each participant's interview at the SLB Negeri Semarang lasted approximately 45 to 60 minutes. To gather information, researchers used a triangulation of sources, specifically other family members and teachers, as well as observations during visiting hours. The concepts of credibility, confirmation, audibility, and transferability are used to evaluate the data's trustworthiness.

3. Study Variables

The dependent variable was personal hygiene. The independent variable was the role of the caretaker.

4. Operational Definition of Variables

Caretaker was someone who looks after a child with the implied or explicit permission of a parent or guardian. Examples of caregiv-

ers include foster parents, aunts, and grandparents (Slack and Strode, 2016).

The caregiving role encompasses the following domains: assistance with household tasks, self-care tasks, and mobility; emotional and social support; health and medical care; advocacy and care coordination; and surrogacy. Each domain has a variety of tasks and activities (Committee on Family Caregiving for Older Adults, 2016).

Personal hygiene was the practice of caring for oneself. It also refers to maintaining the cleanliness of one's body and clothing to enhance one's general health and well-being. Personal hygiene is maintaining body parts like hair, eyes, nose, mouth, teeth, skin, and armpits, among others. It takes skill and consideration to encourage changes in hygiene because it is such a personal topic (Tamiru et al., 2017).

5. Study Instruments

By the research objectives, researchers make research instruments in the form of questions that will be distributed to participants. This guide was prepared not only for the study but also for the problem under investigation.

Due to the limitations of the researcher in recording all the interview processes, a recording device was used to assist the researcher. The recording device is used after obtaining permission from the participant.

During the interview process, the researcher made field notes, such as: noting the expressions of the participants and the behavior of the participants and children with down syndrome.

6. Data analysis

The researchers used N-Vivo 12 pro for data analysis. In-depth interviews and observations are used to compile information for a summary, which is then coded into several themes. Summarizing or reducing data focuses on information and provides a more precise picture, allowing researchers to collect

additional data more efficiently. The data gathered allows for broad conclusions about how caretaker behavior aids in the personal hygiene of children with Down syndrome. The data is then organized by displaying (presentation) tables, graphs, or discussions.

7. Research Ethics

The research ethical clearance approval letter was obtained from the Research Ethics Committee of the Faculty of Public Health at Diponegoro Universit, numbering 354/ES/-KEPK-FKM/2022, on September 22, 2022.

RESULTS

1. Sample Characteristics

Participants included ten caretakers who directly cared for children with Down syndrome aged 7 to 14 years. Eight women and two men between the ages of 28 and 54, with education ranging from elementary school to tertiary level, with a predominance of senior high school. Most parents and caretakers are housewives. Most participants have three children. All the participants come from middle-class families. Two triangulation participants were SLB Negeri Semarang teachers. The table below contains additional information (Table 1).

Table 1. Demographic data of research participants

Attribute	Frequency	Percentage (%)
Gender		
Female	2	20
Male	8	80
Group Age (years)		
26-35	2	20
36-45	3	30
46-55	5	50
Last Education		
Elementary school	3	30
Junior High School	1	10
Senior High School	5	50
Diploma	1	10
Profession		
Unemployment	1	10
Housewife	8	80
Snack Seller	1	10

The five themes of the caretaker's role in personal hygiene for children with down syndrome are as follows (Figure 1).

The first theme is developing communication skills with children. Most down syndrome kids cannot understand what their caretakers are telling them to do. The caretaker's job in this situation is to give guidance or instructions as plainly as possible so that the children can understand what needs to be done. The caretaker's patience, though, was put to the

test during this procedure. The following quotes from participants demonstrate this point:

"...I teach him, for example, brushing his teeth, sometimes to interest him so he can focus on what I am saying; that is my way of playing with him, bringing his favorite toy to the bathroom; I even buy a funny-looking toothbrush, by his wishes..." (P9)

"...She cannot perform daily tasks like washing her hair and body with soap,

so sometimes I ask her to make jokes. For instance, when I tickle her while washing his armpits, I tell her that the pain and sour smell make her armpits hurt, so she will understand if she

needs to use soap in that area. I choose to do this rather than argue with her because doing so would drain my emotions..." (P8)

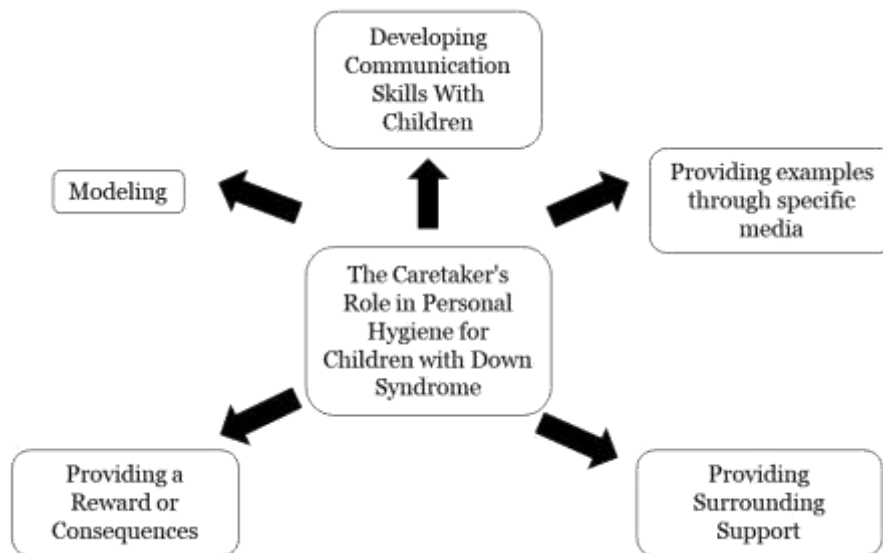


Figure 1. The five themes of the caretaker's role in personal hygiene for children with down syndrome

The second theme is providing examples through specific media. Because children with down syndrome have cognitive limitations, it is necessary to provide examples of personal hygiene practices such as bathing, washing hands before eating, and leaving the bathroom.

"...aside from speaking directly, I try to find examples for children; for example, I look for cartoon broadcasts or some kind of video on YouTube that teaches how to brush her teeth properly, what is the correct order for bathing, washing hands, and so on..." (P10)

The school also does this; for example, before entering class, the teacher teaches the children to wash their hands first, accompanied by the proper steps and facilitated by the availability of sink facilities. They had water and soap running in front of the

child's classroom.

"...here, the main thing is taught for personal hygiene such as hand washing, because it is the basic thing, we are taught to clean first through clean hands, so we always and continue to teach what hand washing with soap is like, every time you go to class, take a break. We also demonstrate how to brush their teeth...." (Teacher).

The third theme is providing surrounding support. This theme focuses on what neighbors or other family members can do to help kids develop independence in caring for their hygiene. The child will feel secure and want to be more independent in maintaining personal hygiene if the family is there to support them.

"...my child has begun to menstruate, so the mother is the one who looks after him. To help the child under-

stand, the mother repeatedly demonstrates how to put sanitary pads on one's underwear, clean one's genitalia, and even clean one's pads. (P7)

"...his older brother or father will frequently compliment him, saying things like, "Wow, what a great brother, can brush his teeth, or sometimes when there is much applause for him when he is finished, he can do something like that, and it makes him happy..." (P9)

The fourth theme is providing a reward or consequences. This theme focuses on how a child with Down syndrome performs his personal hygiene responsibilities.

"...sometimes he does not want to shower; he wants to keep playing. Once he has taken a long shower, he enters the bathroom, but the shower is not clean. To avoid this, I occasionally entice them with toys or can act silly with their cellphones..." (P4)

The fifth theme is modeling. Children should be given clear instructions by way of concrete examples.

"...If I take a shower, I take a bath together because it is a fellow woman, so it is okay; I take a shower in the morning, I take her all, I teach her the sequence of bathing, how to wash, how to take the soap, how to use the soap to dry, and I even practice the body with a towel right away..." (P2)

DISCUSSION

This study shows that the role of caretakers is one of them in developing children with down syndrome communication by inviting children to play or joke. This role will further increase the child's confidence in doing his job, one of which is personal hygiene. Not in a rude way or by yelling because caretakers who prioritize emotions in teaching personal hygiene are difficult for chil-

dren to catch (Backović and Milić, 2021).

Parents and caretakers must employ media-use strategies when teaching personal hygiene to kids with down syndrome. There are two categories of learning materials: planned and those that can only be applied to the task. Resources for planned learning are specifically created to meet the needs of children for formal education and call for exceptional support. Use-based learning resources, however, are not explicitly made for learning (Mais, 2016). Giving children with down syndrome learning options that are simple for them to understand is the responsibility of caretakers. Because children with down syndrome are more interested in visual issues, participants in this study chose media that captured children's attention, such as cartoon series or shows on YouTube (Faught et al., 2016). Caretakers can sometimes be helped by their child's use of communication devices (like the iPad) as a valuable way to share stories, especially when their child's speech is subpar, to involve children in essential activities (Murphy et al., 2017). According to Couzens and Cuskelly's research, children with down syndrome can perceive through visual-spatial means (Couzens and Cuskelly, 2013).

Children's interactions with their surroundings, such as other family members who reside in the home, need to be improved by caretakers. With the family's strong desire and independence to provide personal hygiene care for children with Down syndrome acting as the motivating factor, this is possible (Rahayu and Syafar, 2015). Children with special needs can become independent in maintaining personal hygiene if those around them show appreciation. According to research findings from Ita et al., increased personal hygiene care for kids with special needs is significantly correlated with support in the form of appreciation

(Pursitasari et al., 2020). Children with special needs benefit greatly from social support, which helps them feel like other kids. Their encouragement, enthusiasm, and support significantly impact kids' psychology (Bakhshi et al., 2018; Floyd and Olsen, 2017).

If the child can carry out personal hygiene practices, for example, by washing hands, brushing teeth, or other things, giving gifts or rewards can make children interested in repeating this success. Moreover, consequences to children if children cannot complete personal hygiene tasks such as bathing that is not clean or still has soap residue, for example, not being allowed to watch children's favorite shows (Kementrian Pemberdayaan Perempuan dan Perlindungan Anak Republik Indonesia, 2019). In line with the study by Wehmeyer in, Suparmi et al. (2018) assert through the self-functional of self-determination that children with disabilities can develop independence by giving gifts, environmental support, opportunities, and support, all of which affect intelligence (Suparmi et al., 2018).

Caretakers' direct modeling in personal hygiene practices, such as bathing. Here, the caretaker gives specific instructions and gives the child an illustration of how to behave independently, such as what to do first when taking a bath (Suparmi et al., 2018). Faragher et al. study's supports the findings from Wright et al. research's that children with Down syndrome can learn by imitating models of things that are actually done (Faragher et al., 2020).

AUTHOR CONTRIBUTION

Rifka Purnamawati, as chair, is in charge of preparing proposals, all administrative research documents (research permits), and supporting documents in data collection, data analysis, report creation, and article draft-

ing. Zahroh Shaluhayah and Antono Suryoputro provided guidance from proposal writing to data interpretation and publication.

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CONFLICT OF INTEREST

The authors declare that the study was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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