



Menstrual Hygiene: Barriers and Support for Adolescents with Intellectual Disability

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Abstract

One important element of reproductive health is a supportive community that provides key resources with the aim of empowerment and active and voluntary participation. Without these components, people with disabilities may experience barriers. The purpose of this study was to identify the barriers of family resources, teachers and health workers in supporting adolescents with disabilities in menstrual *hygiene* behaviour. The research method used was a qualitative case study by conducting an *in-depth interview*. Results for the barriers of tunagrahita: Information provided must be repeated; Accompanied when in the washroom; Not yet accepting themselves if they are already experiencing menstruation; Not attending school. Family barriers: Did not remind the menstrual schedule; Did not provide opportunities to practice; Stopped providing information. Teacher barriers: Difficult to provide information because the term is considered taboo by the family and the mentally retarded. Health worker barriers: Adjustment to programme substitution; Post COVID-19 adjustment; Limited media and interaction skills. Results obtained for organisational and community resources, namely: All families provide social support; The way families and teachers identify the schedule and gestures of children with disabilities during menstruation is through themselves because the menstrual schedule is the same or close together, and other common characteristics. Activities related to menstrual *hygiene* at school are still uneven; Families feel the need to be given information; Schools are willing to facilitate; Health workers feel the need to be given training on how to interact and supporting media.

Keywords: Barriers, Support, Adolescents, Tunagrahita, Menstrual *Hygiene*

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Doi # <https://doi.org/10.62877/96-IJCBS-24-25-19-96>

1. Introduction

Community attitudes towards disability vary from sympathy to indifference and exclusion [1]. Makassar City has the highest number of people with disabilities at 2.78% when compared to other regions in South Sulawesi (Sulsel). The Regional Planning, Development, Research and Development Agency (Bappelitbangda) of South Sulawesi in 2022 stated that the number of disabilities in Makassar City was 30,373 people or 12.28%. Based on the Basic Education Data (Dapodik) in 2022, the number of students in Sekolah Luar Biasa (SLB) is 1,273 people with a distribution of SDLB as many as 779 people, SMPLB as many as 306 people and SMALB as many as 188 people. Riskesdas (2018) states that South Sulawesi is the third province with the largest number of disabilities in Indonesia at 33.6%. The Ministry of Social Affairs of the Republic of Indonesia (Kemensos RI) in 2022 showed that the number of disabilities in Indonesia reached 16.5 million people, with a proportion of 7.6 million men and 8.9 million women. Menstruation can be a significant obstacle for adolescents with disabilities related to sexuality issues, vulnerability to

sexual harassment, risk of unwanted pregnancy, difficulty managing menstrual hygiene, abnormal uterine bleeding, dysmenorrhoea, behavioral difficulties and mood problems [2]. According to the *Global Menstrual Collective*, menstrual health consists of five essential elements: Access to timely, developmentally appropriate and evidence-based information; Fulfilment of body care through personal preferences, hygiene, comfort, privacy and safety; Adequate treatment for menstrual-related discomfort or disorders; A supportive community that provides key resources with the goal of empowerment; and Active and voluntary participation [3]. Without these components, people with learning disabilities may experience increased risk of infection, difficulty concentrating, bodily discomfort, feelings of embarrassment and decreased levels of school participation during their menstrual cycle [4]. One of the strategies that people with disabilities can use to survive is by involving support from the surrounding environment, such as family, neighbors, relatives, and non-governmental institutions committed to people with disabilities [5]. Based on the

description in the introduction, it shows that adolescents with disabilities are a group that experiences barriers to health, they have a greater dependence on their environment than other adolescents. Indirectly, families need efforts to improve the quality of life of adolescents with disabilities by utilising support from available resources.

2. Materials and Methods

This research is a type of qualitative research with a case study approach regarding the menstrual *hygiene* behaviour of adolescents with disabilities in SLB Negeri 1 Makassar. Family, teachers and health workers were selected by *purposive sampling*, namely individuals who are considered capable of providing *in-depth* information during interviews (*indepth* interviews).

3. Results and discussion

As in table 1 A is a 20 year old mildly retarded teenager who is currently attending SMA Luar Biasa class XII, he lives with his parents and one younger brother, A's mother is a housewife and A's father is a businessman. A had attended a regular primary school but could not adapt and was bullied several times by his schoolmates, A then moved to SLB Negeri 1 Makassar when he was in grade 5. In terms of basic skills, A is able to write and read and is not yet fluent in counting. To attend school, A is driven by his father and mother with a distance between home and school of 4.3 KM. During school hours, A's mother always accompanies A on the school terrace until class is over. N is a 20-year-old moderately disabled teenager who is currently attending SMA Luar Biasa class XII. She does not live with her parents but with her grandmother and two aunts. Her grandmother and two aunts are Quran recitation teachers. N had attended a regular primary school but during the learning process, she had to be accompanied by her aunt in the classroom to copy what her aunt wrote, because of this obstacle N then moved to SLB Negeri 1 Makassar when she was in grade 3. In terms of basic skills, N is not yet fluent in writing, reading and counting. To attend school, N is taken by one of her aunts in turn with a distance between home and school of 3.5 KM using public transport and during school hours her aunt always accompanies N on the school terrace until class is over. R is a 19-year-old severely mentally retarded teenager who is currently attending SMA Luar Biasa class XII, he does not live with his parents but with his grandmother, aunt and younger brother who is autistic. R attended SLB Negeri 1 Makassar from primary school to senior high school. In terms of basic skills, R cannot read, write and count. To go to school, R is taken by her grandmother and occasionally alternated by her aunt when she is not in the office with a distance between home and school of 4 KM. During school hours, her grandmother or aunt always accompanies R on the school terrace until class is over. The causes of communication barriers can be divided into two, namely internal and external barriers. Internal barriers are barriers that come from within individuals related to physical and psychological conditions. While external barriers are barriers that come from outside the individual related to the physical and socio-cultural environment. Referring to the results of the research, the internal obstacles found were that the

information and training given to adolescents with disabilities had to be repeated. This can be seen in the following quote:

"There are things that we repeatedly say like washing. We must always remind them. We have to keep training them, because even though they know, if we don't repeat it. It has to be repeated if it's not, he's ignorant and thinks it's clean. Because once I washed it but I just put it like that, I didn't put it in the bag. It took him a while to understand" (SF, 52 years old, aunty of a person with moderate dementia, 02/01/2024).

There are also adolescents who still do not understand even though they keep repeating it and only wait for directions when using sanitary napkins such as lifting their legs and squatting. In addition, they are always accompanied when in the washroom because they like to play with water. Another obstacle is that adolescents with disabilities cannot accept that they have entered adolescence and must feel and behave in menstrual *hygiene* every month. The external barriers found were that adolescents with disabilities did not go to school when approaching and during menstruation until the third day because parents and teachers were worried about the amount of menstrual blood that came out and avoided social violations such as difficulty controlling behavior by showing their menstrual blood in public. Similar to Januarti's research (2023) which states that barriers can also occur because adolescents with disabilities lack understanding of social rules, making them experience problems in terms of controlling behavior, so they cannot place themselves [6]. Referring to the results of the study, obstacles also occur in the families of adolescents with disabilities, namely never reminding their children's menstrual schedule, not giving them the opportunity to practice independence due to high anxiety, especially when they are in the kitchen and bathroom, thinking to stop training adolescents with disabilities because they never give a positive response to the directions given. Of all the barriers found both internal and external, families and adolescents with severe disabilities have more barriers. This is in accordance with the research of Sukmawati *et al.* (2020) stated that there are many obstacles faced by children with disabilities such as problems related to self-care and health. Seeing the condition of children's limitations in their daily lives, they experience many difficulties, especially in the severe category. Maintenance of daily life really needs guidance. Therefore, schools are expected to be able to provide training and habituation to students to take care of themselves. It is realised that the ability to adjust to the environment is strongly influenced by the level of intelligence because the level of intelligence of tunagrahita is below normal, so in social life there are obstacles. Then the results of the interview with the resource person, namely the teacher of the self-help class of SLB Kartini Batam, that in the implementation of a learning programme cannot be separated from the inhibiting factors of the programme, namely: Students' hand motor skills are stiff so that it takes a long time to train self-help learning; Students sometimes rarely go to school and parents do learning at home because of pity for the child; Emotionally unstable and reluctant to do self-help learning; Parents often let their children not follow up on training and habituation activities at home.

Table 1. Table of Informant Characteristics

Initials	JK	Age	Education	Jobs	Description
NB	P	60	HIGH SCHOOL	IRT	Mum
US	L	74	S1	Entrepreneur	Father
SF	P	51	SMP	Ngaji teacher	Aunty
SS	P	52	SMP	Ngaji teacher	Aunty
AD	P	52	S1	ASN	Aunty
AJ	P	76	SD	IRT	Grandma
AH	L	51	S2	ASN	Principal Teacher
AI	P	44	S1	ASN	SRH Teacher
HB	P	55	S2	ASN	Homeroom Teacher
SA	P	36	S1	ASN	UKS PKM Tamalate
EH	P	53	S1	ASN	PKPR PKM Tamalate

Referring to the research results, teachers stated that to resolve these obstacles, it must be with the cooperation of the family, because teenagers with disabilities spend more time at home with their families than with teachers at school. Teachers also experience obstacles in providing information about reproductive health including menstrual hygiene because the terms used are still considered taboo by families and adolescents with disabilities. This is stated in the following quote:

"It's not easy to give vulgar knowledge, not everyone can accept it, for example, directly mentioning the vagina but people sometimes don't accept it. This means that customs, norms that exist in society are ingrained, it is difficult. For example, mothers don't teach their children like that, so that's the challenge in the field, reproductive health must be promoted, so that's why I said it's not easy. But we must not be pessimistic and still deal with the community" (AI, 44 years old, SRH Teacher of SLB Negeri 1 Makassar, 09/10/2023).

Furthermore, the obstacle of health workers at Puskesmas Tamalate in the field of PKPR is that they have never visited SLB Negeri 1 Makassar to conduct reproductive health screening, counseling or training on menstrual hygiene behaviour of tunagrahita due to the adjustment of the substitution of the person in charge of PKKPR and the COVID-19 pandemic. After the pandemic ended, there were too many activities so that visits to schools including SLB Negeri 1 Makassar have not been carried out. Meanwhile, the UKS field routinely visits SLB Negeri Makassar but only conducts periodic examinations and the formation of little doctors, not related to reproductive health including

menstrual hygiene. The reason why the UKS field has never done this is due to limited media and the ability to interact with adolescents with disabilities. It is stated in the following quote:

"That's what it's been like, because we are confused about what model to convey to the students, well it's the media that doesn't exist. We also do not have techniques, meaning that we have never been trained so that we know how to convey information to children with disabilities. That's me, knowledge may have to be taught, if their teachers are in school anyway, we don't know, so if we go to school it is only limited to services" (SA, 36 years old, Health Worker at Puskesmas Tamalate, 28/10/2023).

This is similar to the obstacles stated in Widaningsih's research (2019), namely the obstacles that exist in the implementation of hand washing with soap education for children with disabilities in Putro Oyotasih Jatinom SLB, namely: Lack of learning equipment and media; Lack of intellectual abilities of children with tunagrahita; Researchers must explain and practice repeatedly [7].

3.1. Organizational and Community Resources

Maintaining menstrual health is very important, but because adolescents with intellectual disabilities have intellectual limitations, support from organizational and community resources is needed for independent menstrual hygiene behaviour because adolescents with disabilities also have the right and obligation to develop in order to live independently. All parties including families, teachers and health workers must be able to accept the existence of

adolescents with disabilities. This is faced so that adolescents with disabilities have high motivation and confidence in living an independent life according to their abilities. Referring to the results of the study, someone who helps teenagers with disabilities in menstrual hygiene behaviour is their mother, father, aunt, grandmother and teacher. This is similar to Kusuma's research (2021) that the role of family is very influential in determining how children's health will be in the future. Mothers or other female relatives can take on a greater role than fathers, especially in girls' development, due to gender similarities and past experiences [8]. The way families and teachers identify the schedule and gestures of adolescents with disabilities during menstruation varies, namely through themselves because the menstrual schedule is the same or close together, the disabilities look weak, emotional, angry, indifferent, do not move much, and complain of abdominal pain. Then for activities related to menstrual hygiene carried out at school, the family stated that they had attended meetings in the hall regarding personal hygiene, including menstruation, but there were also families who stated that they had attended meetings in the hall but not menstrual hygiene counselling, adding that it was possible that when there was health counselling on menstrual hygiene behaviour, they were not present. According to Wilbur et al. (2021), this resulted in menstrual hygiene information delivered at school being unevenly distributed because participants with disabilities who were not attending school could not receive the information [9]. One participant was sent home from school at the onset of menarche, and this marked the end of her formal education, which could negatively impact her life chances. Caregivers who cannot leave the house due to caregiving duties are also at a disadvantage as they cannot access information shared in the community. The school stated that it is willing to facilitate a special room if there are parties who want to conduct counselling and has also formed a counselling team consisting of teachers. This is stated in the following quotation:

"We have a group here, 5 people who are tasked with sexual health and disability, one of their roles is to provide important information and intensely communicate to homeroom teachers to convey that small counselling is still running, also gather parents, convey that there are activities regarding reproductive health. Secondly, during the ceremony, I convey to the teacher or homeroom teacher that please pay attention when the children have symptoms of illness, let us anticipate together, as a delivery. If the direct action is how the child is in the class, the teacher knows. But we still convey and facilitate" (AH, 51 years old, Principal of SLB Negeri 1 Makassar, 09/10/2023).

Meanwhile, although the health workers at the Tamalate Community Health Centre in the field of PKPR and UKS have never conducted menstrual hygiene counseling for adolescents with disabilities, they still carry out basic health examination activities regularly such as measuring height, weight, immunisation, giving blood enhancement tablets and forming little doctors. Puskesmas Tamalate health workers also hope that in the future there will be training on how to convey information to adolescents with disabilities. The results of a study in Pakistan found that a school-based sexual health programme proved to be acceptable, feasible and

effective in improving knowledge and skills. Utilising video as a tool in providing health education involves the use of the senses of hearing and vision, with the aim of increasing understanding of the information conveyed because video media in health education has been proven effective in increasing individual knowledge, perceptions and behaviour towards the messages contained in the video [10]. In addition, Lusiana et al. (2022) stated that the training model for reproductive health service interventions in people with disabilities can be carried out by implementing education and training sessions for 1.5 hours for adolescents with disabilities and one session for families in the middle of the programme. The use of language in education and training programmes should be simple, structured, and concrete. The realisation of the pedagogical methods developed should be clear to facilitate relevant programme training [11]. Nei's research (2020) recommends the stages of a sexual behaviour education approach that can be carried out, namely: Practitioners open the meeting by building a good rapport with the subject with the aim that during the process of intervention activities a comfortable relationship is established between the practitioner and the subject [12]. Explaining and providing information to the subject about maintaining body hygiene when bathing. Explaining and introducing the parts of the human body in full, explaining and introducing the concept of male and female sex differences, and explaining personal body parts that should not be seen and touched by anyone; Explaining the parts of your body that can only be touched by your grandmother and mother, such as when bathing you, cleaning up after defecation, maintaining hygiene during menstruation, and when going to the doctor accompanied by your grandmother / mother; Explaining to the subject with the affirmation "say no when" other people touch your private parts, other people ask to undress in front of him, other people show their private parts and other people show you naked films or photos; Explaining to the subject to behave according to gender-appropriate norms. Such as the use of bathrooms, bedrooms, which places are allowed to undress and which places are not allowed to undress.

4. Conclusions

Each teenager with a disability has different characteristics, tailored to their abilities and categories of disability, namely mild, moderate and severe. Furthermore, not all adolescents with IDD live and are cared for by their parents, some are cared for by their aunts and grandmothers. Adolescents with dementia: Information and training must be repeated; Accompanied when using the toilet; Unable to accept themselves if they are menstruating; and Absent from school. Family: Not reminding the menstrual schedule; Not giving the opportunity to practice because they were worried; Stopped giving information and training because they did not get a positive response from the directions given. Teacher: It is difficult to provide information because the terms used are still considered taboo. Health workers: Adjustment of substitution of the person in charge of the programme; Pandemic and post-pandemic Covid-19; Limited media and interaction skills.

Organizational and Community Resources

Someone who provides support: mum, dad, aunty, grandma and teacher. The way families and teachers identify menstrual schedules and gestures is through themselves because menstrual schedules coincide or are close together, tuna looks weak, emotional, angry, ignorant, does not move much, and complains of abdominal pain. Activities related to menstrual *hygiene* carried out at school, some families stated that they had and some never had. Families felt the need to be informed because they expected information from other parties to be more innovative. The school is willing to facilitate a special room if there are parties who want to conduct counselling. Health workers felt the need for training on how to interact with adolescents with disabilities and supporting media for counselling.

Advice

Based on the results of in-depth interviews and discussion of material regarding barriers and support for menstrual hygiene behaviour of adolescents with disabilities at SLB Negeri 1 Makassar, not all adolescents are independent in menstrual hygiene behaviour, so the advice given is that families, teachers, and health workers continue to train and provide social support, opportunities and trust to adolescents with disabilities to behave menstrually *hygiene* without assistance.

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