

## **The Effectiveness of Social Stories and Video Modeling in Improving Self-Care Skills in Female Adolescents with Mild Intellectual Disabilities during Menstrual Periods**

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## **The Effectiveness of Social Stories and Video Modeling in Improving Self-Care Skills in Female Adolescents with Mild Intellectual Disabilities during Menstrual Periods**

Individuals with intellectual disabilities have different needs related to both sexual education and sexual development. This is caused by their significant limitations in intellectual and adaptive functioning. This is especially true for a female, when these limitations raise problems caring for herself during her menstrual period. So far, intervention to address the inability of a female with intellectual disabilities in taking care of themselves during menstruation is more focused on delivering medical procedures or manipulating the menstrual cycle through the provision of drugs such as the contraceptive pill, but these interventions carry a high risk. Therefore, alternative intervention such as psychoeducation is preferable because this intervention has a low risk. This study was conducted to determine the effectiveness of social stories and video modeling based on social learning theory, and used as an intervention program aimed to improve self-care skills on menstrual care in female adolescent with mild intellectual disabilities. With a single-case study A-B-A design, the mastery of skills on menstrual care were determined using three measures: 1) using a modified menstrual questionnaire; 2) a test on comprehension of self-care skills during menstruation; and 3) a simulation process with two types of sanitary pads (with and without wings) that both were tainted with artificial blood. The result showed: 1) an increase in the score of questionnaires about menstruation; 2) an increase in comprehension on the material; and 3) an increased in behavioral care skills during menstrual period even when the type of sanitary napkins and the bathroom used were different. The intervention program was found to be effective to improve the subject's skills and self-care during a menstrual cycle.

Keywords: menstrual care, mild intellectual disabilities, social learning theory, social stories, video modeling.

### **Introduction**

People with Intellectual Disabilities (IDs) are characterized by significant limitations in functioning before the age of 18, both intellectually and adaptively, especially in conceptual, social, and practical adaptive capabilities (AAID, 2013). These limitations often raise problems in women with IDs when they attempt to care for issues that occur in menstruation. The risk of being subjected to sexual harassment increases when individuals with IDs need assistance from others to clean their bodies. Sometimes, individuals with IDs have difficulty recognizing situations that can lead to sexual harassment. They also do not know how to properly clean and maintain their genitals during menstruation, and they do not have the intellectual understanding to develop positive sexual behaviors (Schaafsma, dkk., 2015) due to impairments in social understanding, behavioral skills, and decision making (Egemo-Helm, dkk., 2007; Miltenberger, dkk., 1999). Therefore, it is important to develop the knowledge and skills to provide effective self-care during menstruation to avoid potential sexual harassment and short- and long-term sexual health problems.

So far, efforts to address the inability of women with IDs in taking care of themselves during menstruation is more focused on delivering medical procedures such as hysterectomy (Rodgers,

Lipcombe, & Santer, 2006; Rodgers & Lipcombe, 2005; Carlson, 2002; Carlson & Wilson, 1994; Richman, dkk., 1986; Kreutner, 1981; Vitello, 1978,) or the manipulation of the menstrual cycle through the provision of drugs such as the contraceptive pill (Hamilton, 2011 and Lennox, dkk., 2005 as cited in Luiselli, 2016; Rodgers & Lipcombe, 2005; Roxburgh & West, 1973; Shropshire, Morris, & Foote, 1967) instead of providing more education on procedures for self-care, menstruation management, and cleanliness.

Medical procedures have been found to have physical, psychological, and social repercussions both in the short and long term. Physical effects such as ovarian dysfunction, blood and cardiac flow disorders (Rodgers, Lipcombe, & Santer, 2006; Rodgers & Lipcombe, 2005; Carlson, 2002; Carlson & Wilson, 1994; Crain, 1980; West, 1977), *hemorrhagi*, *hematoma*, hormonal imbalances, accelerated osteoporosis, infection and abnormal reaction such as allergies to anastesi, *incontinence urine*, early menopause (Bayram & Beji, 2010; Katz, 2002; Baziad, 2001), and decreased response during intercourse (Yongkin & Davis, 2004) were mentioned as medical impacts in the past literature. Psychological effects that have been mentioned were loss, sadness, stress, and depression (Bayram & Beji, 2009; Katz, 2002). There are legal and ethical issues as well as a social impact tied to the medical procedure because the inability of women IDs to perform self-care during menstruation cannot be seen as a disease that requires *hysterectomy* or regular drug consumption to manipulate the menstrual cycle (Rodgers, Lipcombe, & Santer, 2006; Rodgers & Lipcombe, 2005; Carlson, 2002; Carlson & Wilson, 1994; Crain, 1980; West, 1977). Irregular menstrual cycles may also increase the risk of sexual abuse in women with IDs because the risk of pregnancy is no longer a potential effect for the offender (Brady & Grover, 1997 as cited in Luiselli, 2016).

Since interventions with medical procedures have high risks, an alternative intervention with a much lower risk is preferable, such as psychoeducation (Park, 2013; Saltonstall, 2007). Furthermore, the psychoeducative approach of intervention is more in line with the enforcement of the right of individuals with disabilities. These rights are stated in: Law No. 19 of 2011, the constitutional mandate as stated in the preamble of the 1945 constitution which is further stipulated in the 1945 Constitution Article 31 paragraph 1, Law of the Republic of Indonesia No. 20 of 2003 Article 5 paragraph 2, and the Regulation of the Minister of National Education of Indonesia No.70 of 2009.

Providing education about menstrual care skills to women with IDs is the most crucial as well as challenging intervention because it is likely to disrupt her privacy (Ersoy, Iftor, & Iftor, 2009). In addition, the limited intellectual capacity and low social function make the process of discussing and teaching about menstruation more difficult and challenging, which generally includes menstrual cycle, menstrual signs and symptoms, treatment during menstruation, and education associated with the use of menstrual pads (Park, 2013). The unique characteristics of women with IDs need to be addressed with unique teaching methods that address their specific needs. Although the time needed to teach women with IDs these skills, they still need to be given an opportunity to ask questions about and discuss menstruation, and also taught the importance of self-care during menstruation. This education can minimize the problems that usually appear in women with IDs, enable them to function as independently as possible (*National Institute for the Mentally Handicapped*, 1990,) and improve their quality of life (Luiselli, 2016).

According to Luiselli (2016), women with IDs may learn to perform self-care during menstruation through behavior modification techniques. Previous research on this topic by Richman, et al., (1984), Richman, et al., (1986), Epps, Stern, & Horner (1990), and Ersoy, Iftar, & Iftar (2009) focuses on training the women with IDs on menstruation-appropriate behavior and not integrating it with knowledge as Klett dan Turan (2012).

Women with mild IDs are generally more independent in performing self-care during menstruation as compared to those with moderate IDs who still need the supervision of caregivers or those with severe IDs who are completely dependent on caregivers (Joshi & Joshi, 2015). Therefore, it is important to provide individualized instructional plans that are appropriate to the level of understanding of each woman so that it is easier for the woman to understand and apply the lessons (Güven & İşler, 2015; Van Dyke, McBrien, & Sherbondy, 1995). Learning will be more meaningful when women with IDs understand the benefits of self-care and implement the learning through appropriate exercises, especially those learned by the modeling of behavior. A behavior modification intervention program that is based on social learning theory (SLT) was implemented in this research. Specifically, the current research is interested in the effectiveness of social stories and video modeling strategies to improve the skills of care during menstruation in the female adolescent with mild IDs. Through this intervention program, the subject will be exposed to structured information about self-care during menstruation through a video show, which was adjusted to the subject's intellectual ability and needs. The intervention program will be implemented both in the school and at home. The effectiveness of the program will be higher if it is taught in the subject's daily environment. In addition, researchers will also involve the caregiver in order to create comfort as well as to anticipate the possibility of interference related to the subject's concern about privacy, as the intervention is related to a very personal area.

## **Methods**

### **Participant.**

The inclusion criteria were: a) female; b) aged 10-13 years (early-stage adolescents); c) have begun menstruation; d) IQ score ranged between 50-55 to 70 or diagnosed with mild intellectual disability; e) experienced limitations in adaptive functioning, particularly problems in self-care during menstruation; f) caregivers who have a complaint regarding the subject's ability to perform care during menstruation; g) no motor problems; h) able to follow simple instructions; i) currently not undergoing any medical procedure aimed at stopping menstruation or any other medical treatment that can disrupt the menstrual cycle.

The research subject has the initial name, M. She is undergoing grade 7 SMPLB. She is an orphan who lives in an orphanage. She is a 13 year old who has IQ = 54 (based on Wechsler scale) which means that M's current intelligence is considered a mild intellectual disability level. It is also known that M's motor skills and socialization skills are developing according to her age, while her communication skills and everyday life skills are below the average of her age (assessed with VSMS).

A problem faced by M during menstrual cycle is sometimes the pads are put in the wrong position, with the adhesive side of the sanitary napkin on top. In addition, she prefers to hide her used pads instead of washing her underwear thoroughly and throwing the used pads away. Whenever M is asked to wash her used sanitary napkin and her underwear by the caregiver, she

is willing and able to do so but does not get them clean. M is not happy with the washing activity, and often cries while washing if the nanny asks her to wash thoroughly. . When disposing the used sanitary pads that have been cleaned into the trash, she did not wrap it first. Her caregiver needs to ask M to repeat the disposal properly, by taking the plastic, putting the pad into the plastic, then discarding it. The caregiver also has not applied the reinforcement to the correct behavior shown by M.

### **Research design.**

The current research employed a single-case study design (single-case experimental designs) with A-B-A type.

### **Intervention program.**

Social stories and video modeling were two strategies chosen as parts of the intervention program aimed at improving M's self-care skills during menstruation. The social stories about the concept and skill of treatment during the menstrual period used in this intervention program were adapted from Klett and Turan (2012).

The preparation of the social stories script is carried out through the adaptation process of the social stories intervention program developed by Klett and Turan (2012). The name of their social stories intervention program is Taking Care of Myself and there are three sessions: Growing Up, My Period, and How to Take Care of My Period (Klett & Turan, 2012). To measure the success of the intervention program, Klett and Turan (2012) provide the subject with a checklist of nine items of knowledge about menstrual statements that serve as a pre-test and post-test, 20 question items to test the subject's understanding of the content of the intervention program, simulation of care skills during menstruation that is done at the end of third material meeting at least three times. The process of adaptation of the instrument to be used, is done by referring to Beaton et al (2000) cross-cultural adaptation procedures consisting of four stages: initial translation, translation synthesis, reverse translation, expert review, and pre-final instrument test.

A videographer was involved to make the video. M does not know the model used in the video. Before the shooting process, the researcher first briefed the videographer and the model with the purpose of the project and the behavioral targets that will be turned on in the video.

The video was made in the bathroom of a medical personnel located in the institution where M lives. In addition, the staging of the video in a place that surrounds the subject's environment usually used for activity helps the subject remember the material more easily.. Before shooting, the researcher did a little modification of the room by putting a mini container near the bathroom so that subjects can be more independent in self-care skills during menstruation. The videographer begins filming the model performing the story in the script after the researchers say, "I will replace my own sanitary napkins," and finish after the researcher uttered the phrase, "If so, I came out of the bathroom and locked the bathroom door."

The final product of this entire process is a video view. The video is adjusted to the specific needs of M and contains everything the researcher has gathered that includes subject photographs, her caregiver's photographs, supporting pictures, and video modeling tapes that provide knowledge about growth, menstrual experience, and skills treatment during

menstruation. The video also features a narrator's voice. The narrator reads the script at a loud volume and with an enthusiastic tone intonation with the goal of maintaining the subject's interest while watching the video. At the bottom of the video is a subtitle written in Calibri font, size 18, and on each impression no more than three lines of writing captions. In addition, the video also included instrumental music played in the background. Total video viewing time is approximately 10 minutes.

Considering the attention span and the recall ability of M, the duration of the video, and the experience of Klett and Turan during their previous research procedure (2012,) the researcher chose to teach one piece of material per day, perhaps more if she was enthusiastic about the learning process. Therefore, this intervention program was designed to be conducted in six days. Each meeting will last approximately 10 - 40 minutes. If the researcher has not seen any progress in M's comprehension about the material during the planned time, more time will be added.

Researchers have arranged the contents of this intervention program in the one intervention module. The intervention module contains a series of activities that will be undertaken during the intervention program, the materials to be provided, specific learning objectives, delivery methods, tools, and materials needed to support the implementation of the intervention, as well as indicators of success.

### **Measures**

To measure the effectiveness of the SLT based intervention program in improving the skills of research subjects related to menstruation, the researcher developed three measures: 1) a modified menstrual questionnaire; 2) a test of comprehension on menstruation; 3) a simulation process of self-care during menstruation to be performed both before and after the intervention program, using two types of sanitary pads (with and without wings) that are both stained with artificial blood.

Researchers first conducted a need analysis to determine if the subject met the inclusion criteria. Then, baseline measurements were collected using an observation checklist when M was in her menstrual cycle and performing self-care behaviors. The observation checklist was created by the researcher based on M's ability, after discussion with the head of the orphanage.

After collecting baseline data, the intervention program was implemented. Before the intervention program started, the researcher administered a pre-test to gauge knowledge about menstruation. On the first, third, and fifth day, the researcher gave M the first and second lessons, and administered to the subject short quizzes consisting of four questions related to the material. On the second, fourth, and sixth day, the researcher gave the subject the third lesson, and administered a longer quiz of 15 questions related to the material. The subject also performed the simulation of self-care during menstruation after being given the lessons and answering the questions. The subject began the simulation with a verbal instruction from the caregiver. "Change your sanitary napkins!". After the intervention program finished, the researcher gave a post-test.

Researchers used a laptop to play the video and equipped with loudspeakers to enhance the sound. During the simulation of menstrual care skills, the researchers also provided a mini container in

the form of two drawers holding sanitary napkins, plastic bags, and panties that have been stained with a mixture of cornstarch and red food coloring.

Each time the video began, the researcher asked the subject a specific question to catch her attention, such as, "I have a great video that I've created for you. Do you want to see it with me and mama?" or "Now sit yourself down nice and neat. If you're ready to watch, I'll start playing the movie," or "I have another video like the one yesterday. Do you want to continue watching it?", and "This video will be longer than the video yesterday, so you need to watch it carefully in order to understand." When a research subject indicated readiness through verbal or body language responses, the researcher started the relevant video. Then before the subject is given the short quiz about the material by the caregiver, the researcher inquired about the readiness of the research subject, such as, "Now it's time to answer the question, are you ready?"

Reinforcement was given to M in the form of praise, such as "Clever child!" or "Great child!", and positive feedback, such as giving her two thumbs up. Each lesson the researcher brought a snack of chocolate, in order to express appreciation for M's presence with. In addition, the researcher also provided a token to M at the beginning of the lesson that she could exchange with the prize she wanted according to the agreement.

**Follow-up Phase.** The follow-up stage consisted of observation and started when M is menstruating.. The purpose of this stage is to obtain information on the extent to which the behaviors provided during the intervention program persist.

## Results

The result showed an increase in the scores of the questionnaires about menstruation, an increase of a comprehension on the material, and an increase in behavioral care skills during menstrual period although the type of sanitary napkins and the bathroom used are different. Further explanation can be seen in the figure below.

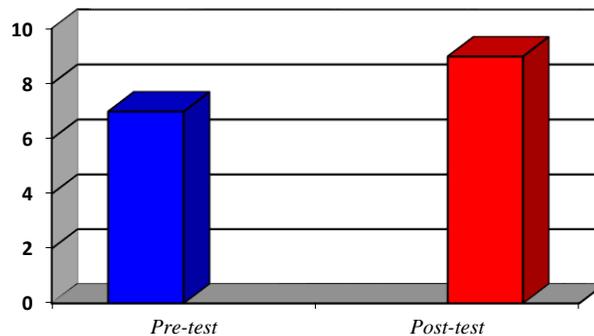


Figure 1. Comparison of Pre-Test and Post-Test Questionnaire Regarding Menstruation

Figure 1 shows the number of questions related to menstruation answered correctly at pre-test and post-test. Before getting the intervention program, M scored a 7 of 9 (77.78%) and after getting intervention program knowledge of research subjects around menstruation, her score increased to 9 of 9 (100%).

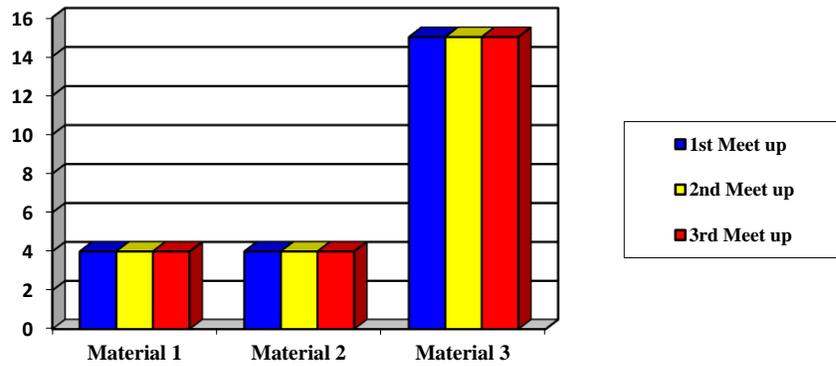


Figure 2. Comparison of Comprehension Test Results on Each Material

Figure 2 shows the number of questions related to menstruation answered correctly on the comprehension test. M always answers the questions accurately on the test of each material from each session: 4 of 4 (100%) on material 1, 4 of 4 (100%) on material 2 and 15 of 15 (100%) on material 3. This means that M was able to absorb and understand information from the material during each lesson.

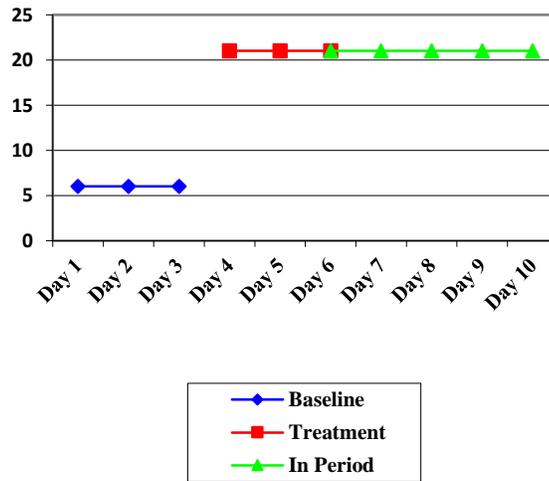


Figure 3. Comparison of Baseline, Treatment, and Post Termination of Treatment (Follow-Up) Measurement Results

Figure 3 shows the number of performed tasks related to self-care during menstrual periods. Before the intervention program, M only completes 6 of 21 (28.5%) tasks and after the intervention program her mastery level increased to 21 of 21 tasks (100%). It means the self-care skills of M during menstrual period increased during the program. She also shows that she can do self-care during menstruation although the type of sanitary napkins and the bathroom used are different.

## Discussion

The social stories and video modeling intervention program developed based on SLT aims to improve knowledge and skills of care during menstruation in adolescent female with mild IDs. The results of this study show: 1) an increase in the score of questionnaires about menstruation; 2) an increase in comprehension of the material; and 3) an increase in behavioral self-care skills during menstrual period although the type of sanitary napkins and the bathroom used are different. This indicated that the intervention program proved to be effective in achieving the objectives of the study. This finding is also supported by the evidence of studies to determine the effectiveness of SLT through the use of a combination of social story strategies and video modeling in an intervention program (Gül, 2016, Halle, 2014, Cigrand, 2011, Wilkinson, 2010, Litras, Moore, & Anderson, 2010, Sansosti & Powell-Smith, 2008, Scattone, 2008). The major differences with this study are: 1) the problem addressed in this study, namely sexual education, especially menstruation; 2) the subject of research in this study, a young woman of early adolescence who also has mild IDs.

The effectiveness of the intervention program in improving the knowledge and skills regarding menstruation on the subject of this study can not be separated from the supporting factors of the study. These are that the intervention program was designed in accordance with the needs of the subject, the preparation for completion of the intervention program needed sufficient time to complete, the intervention program was implemented based on the understanding of the subject, the cooperative attitude and active participation of the subject was necessary during the intervention program, the program was implemented in a conducive and familiar place for the subject, and ended with a follow-up that measured the subject's ability to absorb and repeat the material, as well as the existence of reinforcement.

Aside from these positive outcomes, a limitation of this research is that the implementation of the intervention program is more dominated by researchers rather than by caregivers. According to Klett and Turan (2012), in order for the program of sexual education intervention in individuals with developmental barriers to be optimal, the implementation of the program should be left entirely to parents or caregivers. Researchers decided this after receiving feedback from the orphanage that the institute felt they did not have the capacity to provide intervention programs in children with special needs.

Based on the results and analysis of the research results, it can be concluded that the social stories and video modeling intervention program which is developed based on SLT proved effective in improving the maintenance self-care skills during menstruation in adolescent female with mild IDs.

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