

Menstruation Management on Adolescents with Mental Retardation: A Scoping Review

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Abstract

Menstruation management on adolescents with mental retardation is necessary as self-care to have no bad impact on reproductive organs health and social life. The objective of this study is to find out the evidence based on the management of adolescent mental retardation. This study uses five steps framework which adapted from Arksey and O'Malley. This review focuses on the relevant articles published in 2009-2019. There are 207 articles found and sorted based on inclusion and exclusion criteria, therefore 10 articles are used in this study to extract, compile, summarize and report the results. The thematic analysis has function to identify theme. There are three themes of menstruation management, such as management with menstruation education, the usage of drugs and contraception, permanent cessation of menstruation. The adolescents with low and mediocre mental retardation can use menstruation management along with menstruation education such as counseling and training also using drugs and contraceptives i.e. Depo-Provera IMI, LNG-IUS, COCP, NSAIDs while for adolescent with severe mental retardation can use menstruation management permanently stopping menstruation such as hysterectomy especially countries which have limited resources. Family support, caregivers and health workers in providing information and menstruation education also menstruation management are important in menstruation management on adolescent with mental retardation.

Keywords: management, menstruation, mental retardation

1. Introduction

Menstruation is important process on fertile women as one of development stages on women puberty. The menstruation cycle of adolescents with mental retardation, some studies have shown that there is no significant difference on fertility, age of menarche, menstruation cycle duration compared with normal adolescents. During menstruation, some women will experience physical, psychological, and emotional symptoms called premenstrual syndrome such as irritability, tension, dysphoria, anxiety, insomnia, headaches, mood swings, changes in libido, stomach cramps, constipation and breast pain. Despite of social stigma of adolescents with mental retardation where people consider themselves as disabled and have many problems to overcome the normal physiological changes [1].

Menstruation is a change that requires readiness for young women in terms of knowledge and information in self-care so it has no bad impact for health, especially their reproductive organs. The dependence on parents during menstruation or poor hygiene during menstruation will also impact on adolescent's social life with mental retardation in the long term. This problem requires special attention to prevent social inequality once they become adult. Negative views and speech, stereotypes and stigma are long case for disability around the world if they cannot behave and adapt in the environment well [2]. Based on the Law No. 8 of 2016 the government even guarantees disabled women right on reproductive health [3]. Disabled people should get the same opportunity to

develop themselves independently as human being with dignity. Therefore, it is important to have effective menstruation management for adolescent with mental retardation.

2. Methodology

Scoping review uses the methodology from Arksey and O'Malley (2005) and developed by Levac. There are four reasons to do a scoping review (1) find out the range and nature of study activities, (2) determine the value of full systematic review, (3) summarize and publish findings, and (4) identify study gaps in the existing literature. The stages of scoping review consist of: (1) identifying study questions, (2) identifying relevant studies, (3) selecting studies, (4) mapping data, and (5) compiling, summarizing and reporting results [4].

2.1. Step I: Identifying Study Questions

Identifying scoping review questions, the framework used in this study is PEOs (Population, Exposure, Outcome, Study) [5]. It can identify key concepts of main questions, developing search terms that are appropriate for describing problems and determining inclusion and exclusion criteria. This review specifically aims to find out how menstruation management on adolescent with mental retardation.

Table 1. Framework Study Question

P (Population)	Adolescents and parents of mental retardation
E (Exposure)	Menstrual management, menstrual hygiene, menstrual syndrom
O (Outcomes)	Selecting civilized and effective menstruation management method on adolescents mental retardation
S (Study)	Original research, scopus indexed articles, published in 2009-2019, qualitative and quantitative study

2.2. Step II: Identifying Relevant Studies

This study uses ScienceDirect and PubMed to find relevant articles, using search terms (management AND menstrual hygiene OR menstrual syndrome OR menstrual AND adolescent disability OR mental retardation)

a. Inclusion criteria

The articles published from 2009 to 2019, focus on how coping strategies for menstruation management of adolescent with mental retardation both from the perspective of the mother and individual perspective, using English and Bahasa, no specific country criteria to target, the type of primary article.

b. Exclusion criteria

Review articles (systematic review and literature review) and reports, opinion papers, articles that discuss the causes and effects of mental retardation.

2.3. Step III: Article Selection

a. Prism flowchart

There are 207 articles duplicates $n = 32$ then sorted with the list of PRISMA such as by title / abstract about menstruation management, $n = 62$ articles as the result. Re-

filtering has the function to have best information about menstruation management for adolescent with mental retardation. A full text search of 28 identified articles has been done to filter the contents of the article. Based on the results of the article content filtering, population suitability, methods, and results, and also critical appraisal which has 10 articles to be used for Scoping Review [6].

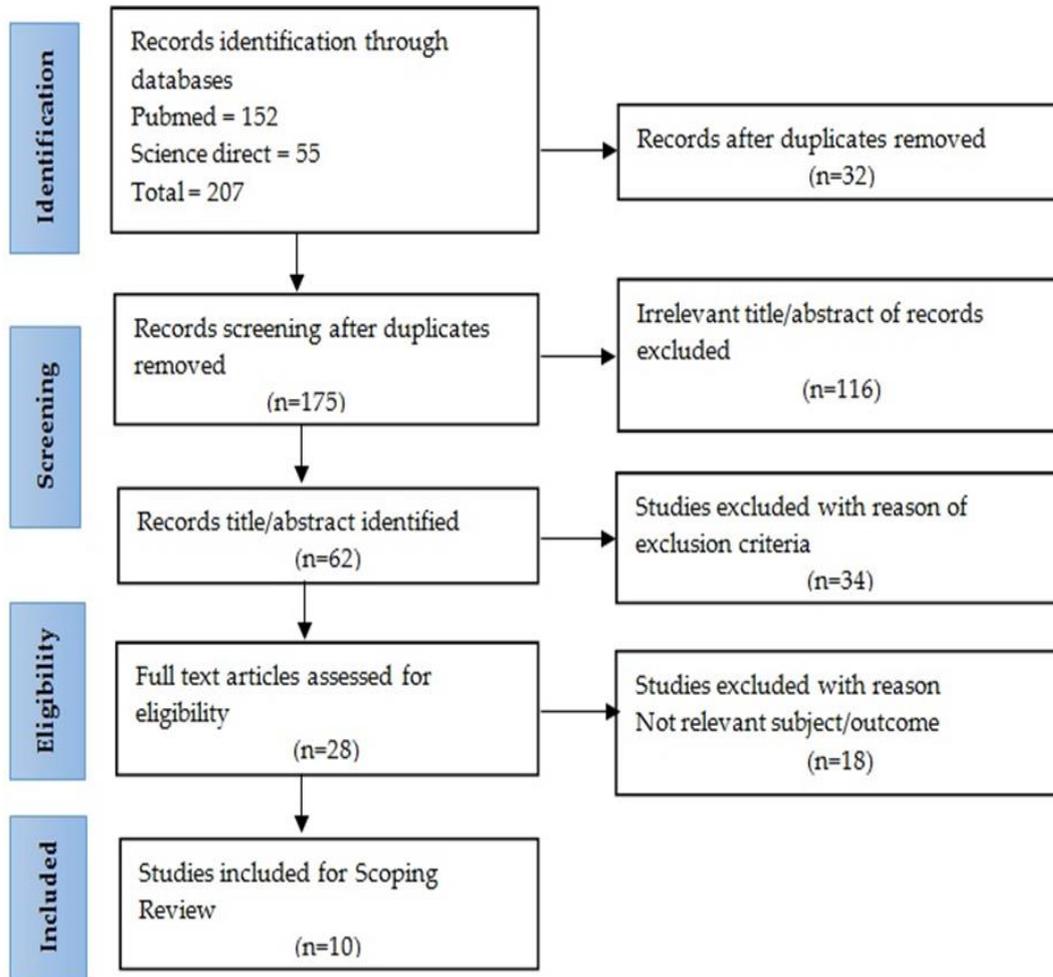


Figure 1. Prism Flowchart

b. Critical appraisal

Critical appraisal is a step to find out the article quality. The tool chosen to assess the quality of articles is a checklist by Joana Briggs from the Joana Briggs Institute.

2.4. Step IV: Data Charting

The data of 10 articles were extracted to include key criteria such as study location, study population, study objective, methodology, and significant findings or recommendations. The writer records the information then compares extracted data independently.

Table 2. Data Charting

Author/ Year	Country	Objectives	Method	Sample	Results
Lin et al./2011	Taiwan	Describing	Cross-	1.152	Women caregivers who

		caregiver awareness of women's reproductive health problems with mental disability	sectional	nannies	have higher education, and those who have experience to be care with women's reproductive health with disabilities that tend to have a higher awareness of reproductive health.
Chalermchockcharoenkit/ 2015	Thailand	Evaluating the safety of laparoscopic hysterectomy in mentally disabled youth	Retrospective	849 people	Laparoscopic hysterectomy is safe and has good results for patients with mental disabilities. This procedure might be a viable option for inducing amenorrhea in adolescent mental disabilities, especially in countries with limited resources.
Kupper/2018	UK	Assessing water access, sanitation and hygienism (WASH) of youth with disabilities.	Case control	707 cases, and 465 control	Persons with disabilities experience greater difficulties in accessing sanitation facilities and practicing hygienic behavior from their normal counterparts.
Altundag & Calbayram/ 2015	Turkey	Teach retarding pad puppets to teenage female retardation students during menstrual periods.	Quasi-experimental	54 people	Training youth with mental disabilities can help them to have clean environment.
Burke et al./2010	USA	Identifying gynecological care problems for adolescent disabilities	Retrospective	44 people	The most common problems experienced by adolescent disabilities are complaints of irregular bleeding and mood / behavior changes.
Cuah et al./ 201	Australia	Reviewing the application of menstrual suppression in adolescents with mental disabilities,	Retrospective	80 people	Studies support the use of COCP as first-line management in achieving menstrual suppression. LNG-IUS becomes the choice in the second line.
Kirkham et al./ 2013	Canada	Observe the development of methods of	Retrospective	300 people	The most commonly chosen initial suppression methods were oral

		menstrual suppression in adolescents with mental disabilities			contraceptive pills (OCP) (42.3%) followed by sanitary napkins (20%), pregnant management (14.9%), depo-medroxyprogesterone acetate (DMPA) (11.6%), and intrauterine levonorgestrel (LNG-IUS) (2.8%).
Leek et al./ 2019	Australia	Review appropriate modalities for menstrual suppression of mentally disabled youth	Retrospective	68 people	Depo-Provera IMI is the most successful modality used to achieve menstrual suppression followed by LNG-IUS. COCP is the most successful medical treatment in achieving menstrual suppression.
Chou & Lu/2012	Taiwan	Look at the experiences and needs of mothers while managing teenage mental retardation	Qualitative	12 mothers with adolescents mental disability	Limited support makes mothers develop their own strategies for managing their daughters during menstruation. hysterectomy or use of drugs to stop or delay menstrual bleeding has never been done by mothers. finance to buy sanitary napkins or diapers during menstruation is a necessity with significant results.
Zacharin, Savasi & Grover/ 2010	Australia	Assess the impact of menstruation on adolescent mental retardation and their families.	Cross-sectional	103 families with adolescents mental disability	Menstruation adolescent with mental retardation is the same with other adolescent generally. There is a high level of parental anxiety about the effects of menstruation, especially adolescents who experience severe mental retardation. medical therapy may be needed but lack of information for the family. Health workers must be active in providing education to families and adolescents with mental retardation.

2.5. Step V: Arrange, Summarize, and Report

In scoping the studyer's review through compiling, summarizing, and reporting the results using a three-phase approach such as First, the descriptive numerical analysis which includes the characteristics of the article. Second, identifying the strengths and

weaknesses found in the literature through thematic analysis of the study included in the report. The final stage is to review the implications of the findings and their relation to future study, clinical, and policy [4].

3. Results and Analysis

Article Description

This scoping review consists of 10 articles selected from two databases, ScienceDirect and PubMed which were published in 2009-2019. The articles obtained came from (8 articles) developed countries, such as Taiwan (2 articles), USA (1 article), Australia (3 articles), UK (1 article), Canada (1 article) and (2 articles) developing countries such as Turkey (1 article), Thailand (1 article). Articles taken in this literature are articles with Q1 quality (8 articles) and Q2 (2 articles). Articles Grade articles taken A (10 articles), which means good quality articles. Article study methods are retrospective (5 articles), qualitative (1 article), case-control (1 article), cross-sectional (2 articles), quasi-experiment (1 article).

Mapping Theme

The results of the mapping of menstrual management themes are grouped into three themes, such as management with menstrual education (7 articles), use of drugs and contraceptives (3 articles), permanent cessation of menstruation (1 article).

3.1. Menstrual Education

Menstrual management in Taiwan is mostly influenced by parental experience, caregiver readiness, adolescent mental retardation conditions, and financial burdens [7]. This is supported by several studies from developed countries such as Canada, USA, Australia, and Taiwan mentally retained adolescents who can care for themselves. There is a role of health workers, parents, and caregivers in teaching self-care [8]. Caregivers who have high education and experience helping reproductive health care have a high awareness of the importance of reproductive health [9]. Education start from the parents of adolescents with autism is very important to reduce health and social problems [10]. The independence of adolescents with disabilities in daily activities such as washing, dressing, eating, toileting, and nursing care is very much related to the family [11]. Family members, caregivers at school and home are important to understand the management of menstrual and labor health professionals also need to function effectively explore the problems the patient and family-related care / concern them, including talking with caregivers, teachers, and other family members, share information on their skills and experience related to menstrual care.

The study in the United Kingdom stated that WASH (Water, Sanitation, and Hygiene) is an important component of healthy living, and the lack of access to WASH will have an impact on health and social affairs [12]. Training by professionals about the need for WASH (Water Sanitation Hygiene) for adolescents with mental retardation and families is one of the most effective ways to promote health to persons with disabilities to improve awareness and improve knowledge [13]. Study in Turkey says training to replace the visual demonstration method for puppets at special educational institutions shows significant improvement in menstrual care skills for students with mental retardation after giving interventions where mental retardation adolescents can easily generalize the menstrual care skills they learn to dolls [14]. In Indonesia, due to no specific curriculum on reproductive health education, the teachers inserted the material in certain subjects such as religion, boarding schools in schools, and other materials that are relevant to reproductive issues or are taught when there are issues raised by students. Reproductive health is still limited to how to maintain the child's relationship with the opposite sex/dating, menstrual problems, wet dreams, and marriage [15].

Based on several studies there are promotions and educational strategies for menstruation such as training of WASH (Water Sanitation Hygiene) and pad replacement training with visual demonstration methods on dolls to realize their menstrual periods and to get self-care habits during menstruation and better education about development reproductive system, situations during menstruation (dirty, clean, etc.), information about pad types (winged, wingless, etc.) and can manage their menstruation.

3.2. Use of Drugs and Contraceptives

Health workers seek to alleviate physical and emotional changes for adolescent mental retardation through the management and / or offer menstrual suppression to improve quality of life by relieving pain related to menstruation, reducing menstruation, and achieving amenorrhea [8]. Contraception is a method of menstrual management in adolescents with mental retardation for reasons for menstrual suppression, preventing pregnancy due to sexual abuse [16]. The choice of menstrual management needs to be considered including (1) the level of cognitive assistance and / or the level of physical disability; (2) related menstrual symptoms; (3) contraindicated with estrogen; (4) concerns for bone density; (5) comorbidities such as seizure disorders; (6) route and frequency of administration; and (7) individual preferences [8].

Study in Australia says that Depo-Provera IMI is the most successful modality used to achieve menstrual suppression followed by LNG-IUS. COCP medical care is the most successful to decrease menstruation [17]. It is also supported by study in Australia that COCP (Combined Oral Contraception Pill) is the most commonly used in therapy, then the second line chooses LNG-IUS (levonorgestrel-intrauterine) [18].

DMPA (Depo-Provera IMI) contraception containing 150 mg of DMPA given 3 months intramuscularly is widely chosen because it causes amenorrhea and reduces cycles and is given four times per year. Depo-Provera IMI has long-term risks such as osteoporosis or reduced bone mineral density, mood swings, and weight gain. Vitamin D and calcium and training can reduce the risk of osteoporosis [17]. Based on this contraceptive study has high effectiveness and in its implementation must require consideration and supervision in each patient where adolescents will easily experience mood swings.

LNG-IUS (levonorgestrel-intrauterine) is a contraceptive that formed like the letter T that releases 20 µg of LNG into the uterus per day for 5 years [17]. LNG-IUS can cause low levels of LNG but locally has high levels in the endometrium and its supporting tissue. This causes stromal decidualization, mucosal depletion, and suppression of endometrial growth which causes the endometrium to be inactive thereby reducing or suppressing the amount of menstrual blood. There were no complications of bleeding, uterine perforation, or infection [19]. Based on LNG-IUS study, it has a high contraceptive effectiveness therapy and can be an alternative to operative measures, such as hysterectomy in dealing with heavy menstrual bleeding.

COCP (Combined Oral Contraception Pill) contains 30µg ethinylestradiol/levonorgestrel which consists of a combination of estrogen and progesterone hormones that reduce pain and control or reduce the amount of menstrual bleeding. Long-term use of COCP has proven to be safe in the general population, but its limitations must be given every day. COCP containing estrogen which gives the effect of decreasing bone turnover or bone density, weight gain, acne and hirsutism, breast pain. Patients and families are advised to take COCP at night to avoid nausea [18]. Based on this study contraception must be regular in the administration of drugs given every day and its effects need to be considered that can improve the risk of premature closure of bone growth so that children become short and the risk of thromboembolism from gaining weight.

Menstrual pain/dysmenorrhea is the most common gynecological complaint in women. Pain during menstruation causes discomfort in daily physical activity. This complaint is related to repeated absence from school or work so that it can interfere with productivity. Analgesia, generally through the use of non-steroidal anti-inflammatory drugs (NSAIDs) can reduce menstrual pain and blood flow and is safe for patients to use [18]. Based on this, analgesia study can be used if you do not want to use hormonal or surgery.

In Indonesia, According to Law No. 8 of 2016 the government even guarantees the rights of women and people with disabilities to reproductive health [3]. Meanwhile, existing health insurance programs also do not fully support these rights. In the aspect of government health services considered less attention to the reproductive rights of people with mental retardation, especially women. It indicated by the absence of policies that support access to have information and reproductive health services for people with mental retardation. So, there is no menstrual management contraception for adolescents with mental retardation and makes parents carry out menstrual management according to their observations.

Based on several studies the importance of ensuring that women get access to good primary health, and assist in making decisions in choosing menstrual management. To improve the health of adolescent reproductive organs, mental retardation, and reduce family burden.

3.3. Cessation of Menstruation Permanently

During menstruation, some women will experience physical symptoms, psychological, and emotional called premenstrual syndrome for example quick anger, tension, dysphoria, anxiety, insomnia, headaches, mood swings, improve emotional sensitivity, changes in libido, abdominal cramps, constipation and pain in the breast. Patients with severe and very severe mental retardation usually cannot verbally express their discomfort [1]. Based on the theory, severe mental retardation adolescents will experience difficulties and the inability to respond and meet their needs. Difficult adolescent communication with severe mental retardation with parents will affect the process of developing cognitive, emotional, and social functions of the child so that obstacles arise in adapting psychosocially so that children have a high risk of suffering from mental disorders.

Hysterectomy is a surgical intervention that is often performed among young women with intellectual disabilities due to it not only combats menstrual-related problems, but can also prevent unwanted pregnancy, pelvic infections, and uterine or cervical disease [20]. The study in Thailand stated that the use of total hysterectomy laparoscopy in young patients with intellectual disabilities is good, decent, and safe as well as from the parents showed a positive response to such actions. It is suitable for patients who tend to be easily agitated. The surgery has been done for short recovery time and full mobilization on the day of surgery with minimal discomfort to the patient [20].

In Indonesia, Hysterectomy must be based on their request after the patient can be informed about various ways of menstrual management and their respective risks, as well as a permanent hysterectomy by Law of Health Ministry Number: 585 / Menkes / Per / IX / 1989 regarding approval of medical measures. In article 1 that the approval of medical action / informed consent is the consent given by the patient or his family or the basis for an explanation of the medical actions to be carried out on the patient and article 9 verse 2 for people with disabilities who shall approve or reject medical action is given to those who are eligible are: parents, legal guardians, and siblings [21]. However, hysterectomy management for adolescents with mental retardation has not been done. It indicated by the absence of policies that support access to have information and reproductive health services for adolescents with mental retardation and makes parents carry out menstrual management according to their observations.

Based on several studies hysterectomy methods are appropriate for inducing amenorrhea for people with severe intellectual disabilities, especially in countries with limited resources and those who propose hysterectomies should aim for the benefit of patients not for their own comfort or public convenience.

4. Discussion

This study only represented seven countries and mostly from developed countries. The studies from other countries are needed, especially developing countries where there is very little study on this. Study methodologies are various, and most are descriptive or exploratory with a small number of samples taken from the clinical service population with mental retardation or comparing adolescent mental retardation with normal adolescents making it difficult to generalize. Most of the study in this scoping review focuses on (1) the role of family caregivers in menstrual management (2) methods of contraception or sterilization of adolescent mental retardation for menstrual suppression. In some cases, caregivers or families carry out menstrual management based on personal experience and do not wish to perform menstrual suppression using contraception or sterility. The needs of caregivers or family and adolescent mental retardation will vary based on the severity of mental retardation which must be reflected in study. Thus, to avoid the study gap the need for additional literature.

Studies should explore the management of adolescent mental retardation. Management is important due to having no adversely affect health, especially in the reproductive organs, dependency with parents during menstruation or poor hygiene during menstruation will also have an impact on the social life of adolescents with mental retardation in the long term [7]. Several studies have examined how the role of family and caregivers in menstrual management of adolescent mental retardation. For example, lack of family and caregiver knowledge and most menstrual management is done according to personal experience [7]-[11].

Study must also explore how the role of families in improving knowledge management and the role of health workers related to the management of adolescent mental retardation. For example, health workers must be proactive in providing health education such as WASH training and pad replacement using puppets, selection of drug methods, and contraceptives (Depo-Provera IMI, LNG-IUS, COCP, NSAID) and hysterectomy for menstrual suppression. This study needs to understand menstrual management to support the needs of adolescent mental retardation itself according to the degree to partial adolescent mental retardation [12]-[14][17]-[18], [20].

The United Nations Conference Convention on the Rights of Persons with Disabilities on December 13, 2006, the resolution contained the rights of persons with disabilities and stated that they would take steps to ensure the implementation of the convention [2]. For example, in Indonesia according to Law No. 8 of 2016 the government even guarantees the rights of women and people with disabilities to reproductive health [3]. The purpose is to advance, protect, and guarantee the equality of fundamental right and freedom for all people with disabilities and the respect on their dignity as unseparated part (inherent dignity).

The general condition of disabled people in Indonesia is still worrisome. Mental retardation patients generally experience decrease of comprehension in a sufficiently significant number. This low comprehension makes mental retardation patients difficult to take care of themselves. The daily life of disabled people still obtains unfair treatment and attitude from some part of family and community. Disabled people frequently are identified as ill people, weak in activities, and their mobility becomes very limited and inhibited. In consequence, they often experience sexual assault and suffers various illness, one of them is reproduction disease [3].

Even though there are efforts to eliminate the discrimination, it is still difficult for disabled people to obtain health service they need included in the form of health information and menstruation management in accordance with their needs. It is because nowadays there are still many people owning wrong assumption about reproduction organ development experienced by mental retardation adolescents who are those who have mental/physical limitation do not need information because the limitation owned and frequently forgotten. The government regulation supposes to manage the rehabilitation, protection, education, and guarantee of violence and must pay more attention on the reproduction right of adolescents with mental retardation.

The problem is that reproduction health education and sex education given at school is limited either the material or the teacher. Furthermore, not all mental retardation adolescents ever or are experiencing education. It means, not all mental retardation adolescents have knowledge about sex and reproduction health. The knowledge which is expected to be obtained from the family and social environment is inhibited at the stigma and prevailing taboo culture [15]. Therefore, menstruation management education is still not maximal yet until the lack of information makes parents do menstruation management in accordance with their observation and never think to do counseling or contraception menstruation management and hysterectomy in Indonesia on mental retardation is not conducted yet.

Based on the reality of disabled people general condition in Indonesia, it is the time for disabled people to have right to obtain respect on their mental and physical integrity based on the equality with other people, included the right to gain protection and health service for the sake of their independence, and in case of emergency. The family that has mental retardation adolescents must get reproduction health service comprehensively, consistently, and continuously in line with individual needs of mental retardation adolescents such as by giving health information, training, selecting menstruation management method and support the family to help access and process menstruation management of mental retardation adolescents. The government's role is also important to make the policy which supports the access of information and reproduction health service for mental retardation adolescents because medical staffs need education and guideline to support the family, nanny, and mental retardation adolescents and ensure they receive their rights.

5. Conclusion

This scoping review identifies 10 relevant publications taken from sources in the last 10 years that discuss menstrual management in adolescent mental retardation. There are three themes of menstrual management in adolescent mental retardation such as menstrual education such as counseling and demonstration training of puppets using sanitary napkins during menstruation, use of drugs and contraceptives such as Depo- Provera IMI, LNG-IUS, COCP, NSAIDs can be the choice of menstrual management in adolescent retardation levels mild and moderate, then permanent cessation of menstruation ie hysterectomy surgery is chosen with severe intellectual disability, especially in countries with limited resources. The importance of family support, caregivers, and health workers in the provision of information and menstruation education and management of menstruation in mentally retarded adolescents to improve health status inequitable and gender-equal manner.

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