

The Disability's Perception In The Sexuality's Need And Reproductive Health In Yogyakarta 2019 – A Scoping Review

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Abstract

Persons with disabilities have the right to reproductive health, to get more protection from layered discrimination, acts of violence and sexual exploitation. The purpose of this study was to map the literature on research activities related to gaps. This study uses the framework of Arksey and O'Malley. The framework used is PEOS using 3 databases, namely Science Direct, Pubmed, and Whiley. The results of the review show that persons with disabilities are also human. They can feel their biological needs. They need specific information and implementation on sexuality and reproductive health.

Keywords: *disability, sexuality and reproductive health*

INTRODUCTION

The disability people constitute important part of the world's population estimated one in every 10 people, total 650 million people. This includes blind and deaf people or have other physical and intellectual disorder or mental health. The disability people are able to be found in every age group between men and women. It is estimated 30% of family live with a close family who has a disability. The most people with disabilities make up 80% of the world's population living in developing countries. While people with disabilities make up 10% of the world's population relatively, 20% of all people living on poverty in disproportionately developing countries. The stigma and access denial to health services, education, employment, and full participation in society build it more likely that the disability people will live in poverty (World Health Organization, 2011).

The disability people are every person who experiences physical, intellectual, mental and/or sensory limitations in the long term which in interacting with environment is able to face obstacle and difficulty to participate fully and effectively with other citizens based on equal rights. The protection of the disability people from the neglect and exploitation, harassment and all discriminatory actions, as well as violations of human rights. The disability people also have the right to reproductive health, accept or refuse the use contraceptive, gain more protection from layered

discrimination and obtain more protection from acts of violence including violence and sexual exploitation (Undang-Undang RI, 2016).

Groups of the disability people are often used by some society to be exploited into objects of criminalization such as act of deception and sexual violence. It is proper for the group of disability are provided equal space in obtaining various public services optimally both health, education and employment (Aulia, 2018). The policy on disability is regulated in law number 8 of 2016 especially in terms of the implementation of honor, protection and fulfillment of the disability people's rights in article 62, namely the government, local government and the private sector are obliged to provide health services without discrimination in accordance with the standard and provisions of laws and regulations. As well in article 62, the policy is obliged by government and the local government provides health workers who have competence and authority in health services for the disability people from first-level health facilities to advanced levels.

Integrated reproductive health services are regulated through minister of health regulation number 97 of 2014 which is conducted based on the needs in every stage of life cycle starting from stage of conception, infants, and children, teenagers, childbearing ages and the elderly. This service is conducted at first-level health facility, which are pointed for enhancing access and the quality of reproductive health service through promotive, preventive, curative and rehabilitative efforts (Ministry of Health, 2017).

The role of midwife in health promotion is as advocate, educator, facilitator and motivator. In her role, midwife conduct an approach to the society who are suspected of having an effect on the success of program by providing education or counseling in nurture and service so that midwife can create harmonious group in facilitating the mutual learning process among groups. The role of midwife is to find and encourage groups to recognize potential and problem which occurs so that the society is able to solve this problem (Erwin, n.d.)

The objective of this scoping review is for mapping literature, exploring information about research activity related topic under study and investigating some problems or gaps in the research area to be studied:

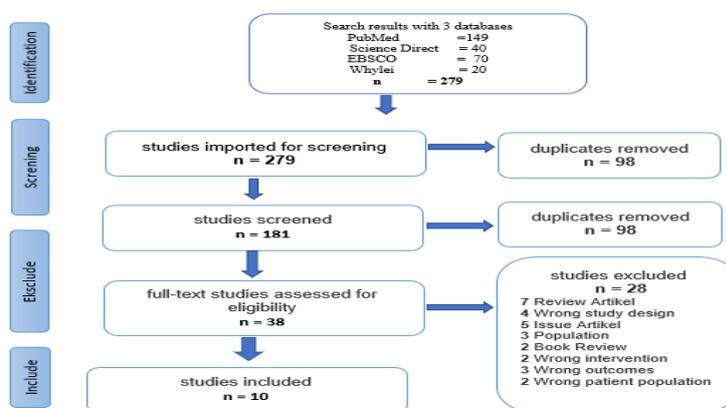
1. Analyzing the disability knowledge about sexuality and reproductive health
2. Exploring the disability perception regarding sexuality and reproductive health
3. Analyzing what efforts can be implemented by government and health workers regarding sexuality and reproductive health in the disability people.

RESEARCH METHODS

The article search used several databases: Pubmed, Whiley, Science Direct and Ebsco, there were 279 articles that had been filtered with several criteria such as year of publication, free full text and the types of articles that are carried out directly when using keywords in search. After being filtered to relevance, there were 181 articles that found and relevant with the title. Afterwards, the further article screening was conducted based on full text for finding the appropriate reference and obtained article that would be utilized for Scoping Review, that is 10 articles, the writer filtered the title and abstract based on inclusion and exclusion criteria. The population (P) focused on Disability. Exposure (E) focused on the sexuality need and reproductive health. Outcome (O) focused on knowing the disability's perception. Study (S) used qualitative cross sectional.

The strategic stages in article search are the first stage is searching on the scope of words, namely the initials or search term entered are 'Disability', 'Sexuality', and 'Reproductive Health'. The second stage is by using all identified keywords or titles, the title is typed on databased: Science Direct, Pubmed, and Whiley. Then, the reference list from all identified report and article is searched for additional research. After going through the words stages as a key. The journal was obtained based on keywords used in the review variables contained in the journal, namely entering keyword that matched with the theme ((((((Disabilitas) OR Disability) AND Sexuality) OR Sex) AND "Reproductive Health") OR "Reproductive Knowledge. Search with more than two syllables are given double quotation marks ("...") for specifying and simplifying the literature search, then determining the period of literature search which in this research is limited to journals published in the las 10 years.

PRISMA



Picture 1. Article Selection

RESULTS AND DISCUSSION

The result of several articles discussed sexuality and reproductive health in the disability people, the writer found from article review used for scoping review data from various countries. In scoping review analysis, there were 9 articles from developing country such as Kampala, Ethiopia, South Africa, Ghana, Philippines, Senegal, Cameroon, India and Cambodia. An article in the category of modern country, namely Australia. The writer used JBI and critical appraisal for assessing the quality of the 10 articles with the result that 8 articles were in the grade A category by using quantitative (cross sectional) and qualitative.

In the developing countries, the results of 9 articles have the same description of the sexual need and health on disability, namely the obstacle due to health and economic access. The limited access to sexual and reproductive health services that is faced by the disability people is limited by many challenges ranging from those related health facilities, economic and social challenges. In contrast to the research conducted by modern country, namely Australia. Its research aims to explore the extent to which sexual expression and interaction with health care providers significantly affect the bad impact on live quality of the disability people. The result of 144 respondents with the disability people found that health care provider who provide access to the disability people were found to significantly reduce the bad impact emotionally.

1. Knowledge

The young people with disability have poor knowledge regarding sexual and reproductive health issues. Most of the respondents less knowledge regarding menstrual cycle or the fertile period where pregnancy is likely occurred. For assessing the knowledge of the disability people about contraceptive method which function to prevent the unwanted risk and information about IMS, the disability people were interviewed. The result showed that most of them have poor knowledge due to accepting unclear information regarding sexual and reproductive health (Kassa et al, 2016).

The reproductive health problem in teenagers do not only occur in young people with disability but also this problem also occurs in teenager without special needs. This is because between teenagers and parents are reluctant to discuss sexual reproductive health issues. Consequently, it causes lack of information regarding sexuality. This problem becomes one of factor occurring the premarital sexual relations that lead to pregnancy (Astuti & Kurniawati, 2020).

In Cameroon, women with disability have limited knowledge of reproductive health. The basic biology such as menstruation is taught in primary school and contraception method as well as sexually transmitted infections are taught in secondary school. However, most of them count on their parents (Mother) or close relative for gaining information and teaching regarding sexual and reproductive health. Some disability women do not have educational access of reproductive because they are not going to school due to financial issues or physical disorder (Bremer, Cockburn, & Ruth, 2010).

When the young people with disability are asked to mention the contraceptive method, they were most familiar with, they answer condom. The low knowledge result is obtained when conducting Focus Group Discussion (FDG) for people with hearing impairments. Several informants reported that when they had sex, they never used condom because they were not afraid of the contagious risk infection that would occur. The information access becomes major obstacle for disability people. So, the knowledge about the dangers of infectious infection for sexual and reproductive health is very low (Burke et al, 2017).

The sexual behavior of teenagers with disability describes the low level of knowledge, the average age of those have sex is 13 years old. It was found that 76.7% of respondents who sexually active did not use safe contraception such as condom. Among the disability people admitted that they did not use contraception because they did not afraid about HIV/AIDS (Obasi et al., 2019).

2. Source of Information

The sources of advice or information regarding sexual and reproductive health are trusted friend about the advice they need. In the lower level, family members become the source of information or women's family for disability women. However, for men with disabilities, they never convey about sexual and reproductive health since they considered that it is taboo (Burke *et al.*, 2017).

Regarding sexual and reproductive health, the respondent with disabilities faced menstruation at age 13 years. Some of the respondent live with their parents. The result of the study showed that 63.9% the major information regarding sexual and reproductive health for disability people are school teacher (Obasi *et al.*, 2019).

There were nine informants of 144 respondents admitted that they had accessed the services or facilities that provided information regarding sexual and reproductive health through society health center or the nearest hospital, public

center such as *LSM (Lembaga Swadaya Masyarakat)*, association of women with disabilities as well as private pharmacies and community health focused on women's health (Burke *et al.*, 2017).

The information on sexual and reproductive health of young people with disabilities in Ethiopia is gained from the main sources, namely television or radio. Besides the information on sexuality and reproduction is accessed through friend, school teacher and health professional (Kassa *et al.*, 2016).

3. The Challenges in Accessing Sexuality and Reproductive Health Services

The lack of confidentiality and anonymity as well as long distances are the major obstacles in accessing health services. The other obstacles are financial, physical access, marital status and religion that make them lack of information and do not know how and where they must gain sexual and reproductive health services (Burke *et al.*, 2017).

The disability people experience obstacles in accessing sexual and reproductive health services such as inconvenience service area for people with disabilities, costs and fear of going alone due to the distance of health facilities (Kassa *et al.*, 2016).

The challenges experienced by PWP in accessing SRH services are grouped by gender, poor physical accessibility, negative attitude of health workers and long queues at health facilities are the major challenges faced by the disability people who strive to access sexual and reproductive health services (Ahumuza, Maovu, Ddamulira, & Muhanguzi, 2014).

The women disability stated that they had various experiences with health workers and health centers. One of the respondents explained that they could have received adequate treatment if they are able to pay for medical expenses and communicated their needs. However, there were also those who find that health workers do not value the disability people like when they asked regarding reproductive health, they were ignored. The other obstacle is the transportation such as taxi often refused to take them to health facilities so make them getting difficulty to access the services they need (Bremer *et al.*, 2010)

The obstacles toward health services for women with disabilities are not only caused by physical disorder but also the intersection discrimination based on gender, socio-economic status become one of factors which weakens access to health service for all women, especially women with disabilities (Lee *et al.*, 2015).

4. Violence and Violation of the Rights for the Disability People

The disability people had faces of sexual violence such as rape, some of respondents reported that they were raped once or several times. This case occurred generally in women with hearing loss or physical disorder. All of those happen in adolescence or pre-adolescence and the doer is often the family member and someone who works in professional facility (Burke *et al.*, 2017).

The fright faced by the disability people in health facilities especially those managed by government, the services and treatments they often gain were discrimination, bad attitudes by health workers so that they do not gain full services rights for people with special needs (Dean, Tolhurst, Khanna, & Jehan, 2017).

The violation of reproductive rights was also faced by women with disabilities, namely the sterilization method recommended by doctors, because this method will inhibit their desire to have more a child. This treatment makes them feel helpless because they are considered incapable (Dean *et al.*, 2017).

Living alone as a woman with disabilities and low economic status is a target for harassment case by the society. The fear of reporting the incident is always related to the absence of social support due to social and economic status factors (Gartrell, Baesel, & Becker, 2017).

5. Social Factor

The society is worried about women with disabilities when they are pregnant, the society is worried about the ability to take care of pregnancy or childbirth, but for the disability people, the society's perception is negative view because women with disabilities are considered burden to society (Bremer et al., 2010).

There is support from friend and family with disabilities, when they want to go to health services facilities, the disability people will be accompanied by friends or family so that they get easier for accessing information they need. (Ahumuza et al., 2014)

The marital status is the major determinant of women with knowledge of sexual and reproductive health, especially contraceptive method information. Not all married or unmarried with disability are invited by society leader in meeting organized by LSM (Gartrell et al., 2017).

6. Health Care Provider

People with physical disorder always need service facilities that make it easier for them such as for accompanying when communicating with doctor or another medical worker. However, the woman's experience with visual disorder faces discrimination conducted by health care provider that is they ignore the disability people sometimes when they are in health center (Burke *et al.*, 2017).

The disability people's perception with health care provider are often negative because they get poor treatment. Some health providers sometime do not speak clearly to the disability people and use language that causes them uncomfortable with services provided. The anxiety felt by health worker is communication, because of the limited training as health providers do not have special skills to deal with people with disabilities (Lee *et al.*, 2015).

CONCLUSION

The limited access to sexual and reproductive health services is limited by many challenges ranging from lack of information access that received so that lead to the lack of understanding regarding biological needs that they must receive.

The disability person is necessary special attention regarding the information and implantation of safe sexuality and reproductive health for them. The information access can be applied in communities that gather many people with the disabilities. Consequently, they get easier for gaining information on their reproductive needs and rights. The disability people are human being who can feel biological needs, negative views of family, the health workers and the parents become the biggest obstacles for the disabilities people who should receive special attention.

This scoping review utilizes a systematic review approach for identifying articles related to reproductive health in the disability people. In identifying this article, the writer utilizes 3 databases, which are narrowed down by using a prism. The result of this article which are close to the topic is used for reviewing. The obstacles in this scoping review the lack of references that investigate the need of the disability people in

reproductive health. The databases used in this review mostly uses pubmed database, since two of the databases are more difficult to access.

REFERENCES

- Ahumuza, S. E., Matovu, J. K. B., Ddamulira, J. B., & Muhanguzi, F. K. (2014). Challenges in accessing sexual and reproductive health services by people with physical disabilities in Kampala, Uganda. *Reproductive Health*, 11, 59. <https://doi.org/10.1186/1742-4755-11-59>
- Aulia, Ayuning & Mieke Savitri. (2018). Association information sources of reproductive health with sexual behavior of adolescents in Indonesia. *International Journal of Health Science and Technology*, 1 (1) 2019. <http://dx.doi.org/10.31101/ijhst.v1i3.1214>
- Arksey, H., & O'Malley, L. (2013). *Appendix 1 : Methodological Framework (Arksey & O ' Malley , 2005)*. 2013.
- Bremer, K., Cockburn, L., & Ruth, A. (2010). Reproductive health experiences among women with physical disabilities in the Northwest Region of Cameroon. *International Journal of Gynecology and Obstetrics*, 108(3), 211–213. <https://doi.org/10.1016/j.ijgo.2009.10.008>
- Burke, E., Kebe, F., Flink, I., van Reeuwijk, M., & le May, A. (2017). A qualitative study to explore the barriers and enablers for young people with disabilities to access sexual and reproductive health services in Senegal. *Reproductive Health Matters*, 25(50), 43–54. <https://doi.org/10.1080/09688080.2017.1329607>
- Dean, L., Tolhurst, R., Khanna, R., & Jehan, K. (2017a). “You’re disabled, why did you have sex in the first place?” *Global Health Action*, 10(00). <https://doi.org/10.1080/16549716.2017.1290316>
- Dean, L., Tolhurst, R., Khanna, R., & Jehan, K. (2017b). “You’re disabled, why did you have sex in the first place?” *Global Health Action*, 10. <https://doi.org/10.1080/16549716.2017.1290316>
- Erwin. (2016). *Peran Dan Fungsi Bidan Dalam Promkes* | erwin ccc - Academia.edu. Retrieved December 5, 2019, from <https://www.academia.edu/9417834>
- Gartrell, A., Baesel, K., & Becker, C. (2017). “We do not dare to love”: Women with disabilities’ sexual and reproductive health and rights in rural Cambodia. *Reproductive Health Matters*, 25(50), 31–42. <https://doi.org/10.1080/09688080.2017.1332447>
- Hunt, X., Carew, M. T., Braathen, S. H., Swartz, L., Chiwaula, M., & Rohleder, P. (2017a). The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people. *Reproductive Health Matters*, 25(50), 66–79. <https://doi.org/10.1080/09688080.2017.1332949>

- Hunt, X., Carew, M. T., Braathen, S. H., Swartz, L., Chiwaula, M., & Rohleder, P. (2017b). The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: Beliefs of non-disabled people. *Reproductive Health Matters*, 25(50), 66–79. <https://doi.org/10.1080/09688080.2017.1332949>
- Kassa, T. A., Luck, T., Bekele, A., & Riedel-Heller, S. G. (2016). Sexual and reproductive health of young people with disability in Ethiopia: A study on knowledge, attitude and practice: A cross-sectional study. *Globalization and Health*, 12(1). <https://doi.org/10.1186/s12992-016-0142-3>
- Kemenkes, 2014. (2013). *Journal of Chemical Information and Modeling*, 53(9), 1689–1699. <https://doi.org/10.1017/CBO9781107415324.004>
- Kemenkes, 2017. (n.d.). Kesehatan Keluarga. Retrieved December 5, 2019, from <http://kesga.kemkes.go.id/berita-lengkap.php?id=35>
- Lee, K., Devine, A., Marco, M. J., Zayas, J., Gill-Atkinson, L., & Vaughan, C. (2015). Sexual and reproductive health services for women with disability: a qualitative study with service providers in the Philippines. *BMC Women's Health*, 15, 87. <https://doi.org/10.1186/s12905-015-0244-8>
- Levac, Colquhoun & O'Brien, K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5(1). <https://doi.org/10.1186/1748-5908-5-69>
- O'Dea, S. M., Shuttleworth, R. P., & Wedgwood, N. (2012). Disability, doctors and sexuality: Do healthcare providers influence the sexual wellbeing of people living with a neuromuscular disorder? *Sexuality and Disability*, 30(2), 171–185. <https://doi.org/10.1007/s11195-011-9235-3>
- Obasi, M., Manortey, S., Kyei, K. A., Addo, M. K., Talboys, S., Gay, L., & Baiden, F. (2019a). Sexual and reproductive health of adolescents in schools for people with disabilities. *The Pan African Medical Journal*, 33, 299. <https://doi.org/10.11604/pamj.2019.33.299.18546>
- Obasi, M., Manortey, S., Kyei, K. A., Addo, M. K., Talboys, S., Gay, L., & Baiden, F. (2019b). Sexual and reproductive health of adolescents in schools for people with disabilities. *Pan African Medical Journal*, 33. <https://doi.org/10.11604/pamj.2019.33.299.18546>
- Setianti, Yanti dkk. (2019). "Media informasi kesehatan reproduksi bagi remaja disabilitas tunagrahita di Jawa Barat." *Jurnal Kajian Komunikasi*, Volume 7, No. 2, hlm. 170-183. <https://doi.org/10.22655-76352-3-PB.pdf>
- Undang - Undang RI, 2016. Retrieved December 16, 2019, from <http://pug-pupr.pu.go.id/uploads/PP/UU.No.8.Th.2016.pdf>