Attitudes Towards Sexuality in Males and Females with Intellectual Disabilities: Indonesia Setting

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Abstract: *Introduction*: sexual and reproductive rights in individuals with intellectual disabilities (ID), particularly in developing countries, are often neglected. Although affected individuals never complained, the problems were found augmented from the affected families. Over the last two decades, parents and professionals acknowledged sexual and reproductive right and try to accommodate these needs. Indonesia, a developing country with a strong religious and culture beliefs may has different perspectives on attitudes towards sexuality in individuals with ID which respect the sexual and reproductive right augmented from the affected family. The aimed of this study was to explore the attitudes towards sexuality on individuals with ID. The findings are expected to contribute to the movement in recognizing sexual and reproductive health and rights (SRHR) in individuals with ID.

Methods: thirty participants were included in this study consisted of supporting staffs of rehabilitation center for disabled individual, parents, religious leaders and community. Participants fulfilled the two sets of Attitude to Sexuality Questionnaires towards individuals with ID (ASQ-ID).

Results: the attitudes towards sexuality in males were found similar with females with ID, age did not play a role in the attitude towards sexuality in ID. Indonesian attitudes towards sexuality in individuals with ID was found the most conservative compared to other countries with the mean of sexual right was 3.7±0.22, parenting was 3.5±0.30, non-reproductive sexual behavior was 3.4±0.49, and self-control was 3.4±0.73.

Conclusion: the attitudes towards sexuality in individual with ID is somewhat negative, strong culture and religious beliefs /and values may have strong influence.

Keywords: Sexual right, reproductive right, intellectual disabilities, developing country.

INTRODUCTION

Intellectual Disability (ID), in the past referred to mental retardation, is a lifelong condition that characterized by a significant impairment in intellectual functioning (ability to understand a new or complex information), to learn and apply new skills and in adaptive behavior that occurs before the age of 18 [1, 2]. The prevalence of ID was ranging from 1 to 3% of population in develop countries [3], although wider variation has been reported based on differences in sampling procedure i.e. diagnostic criteria and tools, study design, and population characteristics. The prevalence was usually found higher in developing countries (low to middle income countries) compared to develop countries. Intellectual disabilities affected 4.5% population in Brazil, a developing/ middle-income country, result of study using better sampling procedure (population-based birth cohort) [4]. There are several aspects that may contribute to a higher prevalence of ID in developing country including birth-related infections and injuries due to health care facilities and inadequate prenatal screening methods.

In general, individual with ID were more risk to have additional physical and mental health problems. Although health care are a basic need, identification of health problem among ID is challenging due to communication difficulties, lack of health care facilities, and inadequate skills of family and health care providers in caring for intellectually disabled individual. Over the last centuries, there has been a movement for individual with ID to integrate into the typical community and addressing equal rights including sexual and reproductive rights [5]. Although sexuality is an essential aspect of human being, in the past it goes with unrecognizing their rights, aspirations, sexuality, and reproductive concerns. Furthermore, people with

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ID often experience with society disregarded and stigmatized to be asexual, lacking sexual drive, incapable of reproduction and unfit marriage partners/parenting. Sexual information was prohibited for them and a great effort had been done to discriminate them and to keep them disinterested in sexual and reproductive activities [6]. In the end of 2000s, individuals with ID have been driven to integrate into the community in order to stimulate typical life experience which may help them improving their ability in communication, socialization, and adaptation.

Within the last two decades, parents and professional have begun work together to find the way to help individuals with ID to recognize their sexual and reproductive health and right (SRHR). Debates and campaigns addressing SRHR are emerging, recognizing individuals with ID as a sexual being with equal rights for sexual right such as sexual pleasure, intimacy, love, relationships, sexual and reproductive choices and parenting [7]. Study of sexuality experience in adult with mild to moderate degree of ID in Spain showed that 84.2% had sexual relationship with another [8]. Significant number of exploratory and intervention research with the purpose of gaining awareness and altering perception of the community and also key stakeholders have been reported positive results. However, the movement that funded and led by mostly non-government organizations were mostly done in high-income countries. Although limited number, research focusing on sexual live of individual with ID within low and middle-income countries have been documented [9]. The recognition of human rights of individual with ID is growing in conjunction with the United Nation Convention on the Rights of person with Disabilities (UNCRPD) in 2006 on the realization of basic human rights including to non-discrimination, to privacy and confidentiality, to be free from violence and coercion, to educate, to get access for information and health services [10].

Republic Indonesia Law were issued in 2016 addressing the right of individuals with disabilities including blindness, deafness, physical, and intellectual disabilities [11]. In article 5 paragraph 1 recognizing the right to health, public service, and getting access for information; while in paragraph 2 was specifically recognized disabled women rights to reproductive health, accept/reject the use of contraception, protection from discrimination, and protection from violence including sexual violence and its consequences. However, two years later (currently) there is no follow up action including technical guidelines and implementation instructions statement from government and related ministries. Indonesia is developing middle-income country, where most population are strongly influence by religion and culture [12]. Parents together with professional who work closely with intellectually disabled individuals in daily basis were initiate the movement to express the need of SRHR. With regards to culture norms and religious values (sexuality and reproductive are prohibited issues by social custom), unlike in develop country, the movement was mostly done politely and firmly in an exclusive gathering among related individual and profession. This study was done to elucidating the attitudes towards sexuality and reproductive right in individual with ID.

METHODS

This study was done in collaboration with Balai Besar Rehabilitasi Sosial Bina Grahita (BBRSBG) Kartini, Temanggung, Central Java, Indonesia, a rehabilitation center for individual with mild to moderate ID (IQ score 70 – 50). Participants were comprised of supporting staff of rehabilitation center, parent representative, religious leaders, and community representative who were more familiar with individual with ID. Each participant was asked to complete the two sets of questionnaire i.e. attitudes to sexual expression of males and females with ID. Thirty (30) participants fulfilled the Attitude to Sexuality Questionnaires towards individuals with ID (ASQ-ID) after the consent form was signed. ASQ-ID was the instrument that developed focusing on attitudes to sexual expression of individuals with ID. The statements were composed of 28 statements and grouped into 4 subscales: sexual right (13 statements), parenting (7 statements), non-reproductive sexual behavior (5 statements), and self-control (3 statements). Each statement was scaled a 6-point Likert scale from strongly disagree - moderately disagree - slightly disagree – slightly agree – moderately agree-strongly agree (1 to 6), the most liberal opinions acknowledged the highest scores [13]. Each person completed their own questionnaires for males and females with ID, those method was applied to ensure an objectiveness of the attitude because many statements were about sensitive issues such as premarital sexual intercourse, masturbation, and homosexual relationship which amongst Indonesian were believed in contradiction with religion and cultural norms. This study was approved by Komite Etik Penelitian Kesehatan (KEPK), Faculty of Medicine Diponegoro University/ dr. Kariadi Hospital, Semarang, Central-java.

The comparison of sexual right, parenting, non-reproductive sexual behavior and self-control between age group were analyzed using independent t-test. The p value < 0.05 was considered significant. Comparison of ASQ-ID with other develop countries where culture and religious belief were less strong had been done to understand the influence of culture and religious belief in population attitudes towards sexuality in individual with ID.

RESULTS

Thirty participants completed anonymous ASQ-ID questionnaires but only 28 respondents completed demographic details of age and only 27 respondents gave information about their sex. This study did not provide the comparison of attitudes towards sexuality between groups of respondent because the number of each group representative (parents, rehabilitation center staff, community, and religious leaders) did not match.

The attitudes towards sexuality in individuals (male and female) with ID in this study was somewhat negative (3=slightly disagree, 4=slightly agree) and there was no different between both sex, attitudes towards sexuality in males and females. Of those, the attitudes towards sexual right was the most positive attitudes compared to other subscales (see Table **1**).

Comparison according to an age groups (<50 and ≥50 years old) was applied in order to incorporate the influence of accessibility to media including social media. The attitudes towards sexuality in ID was not significantly different among both age groups (see Table **2**).

In order to figure it out an attitude of Indonesian who lived in community where culture and religious beliefs were stronger compared to population who live in develop countries, comparison with the attitudes towards individuals with ID in develop countries was done (see Table **3**). The attitude of undergraduate students towards males with ID in Italy, the attitude of

Table 1: Comparing the Attitude Towards Sexuality between Males and Females with Intellectual Disabilities

Subscale	Males	Females	Total	p*
Sexual Right	3.7±0.31 (2.8-4.1)	3.7±0.28 (3.1-4.2)	3.7±0.22 (3.2-4.3)	0.8
Parenting	3.5±0.32 (2.7-4.0)	3.5±0.39 (2.9-4.6)	3.5±0.30 (2.9-4.2)	0.7
Non-reproductive sexual behavior	3.4±0.70 (2.0-4.8)	3.3±0.81 (1.8-4.8)	3.4±0.47 (2.4-4.2)	0.4
Self Control	3.3±1.12 (1.7-5.3)	3.5±1.02 (2.0-5.0)	3.4±0.73 (1.8-4.8)	0.5

Value in the table: mean±standard deviation (minimum – maximum).
*Male vs Female, t-test was applied.

Table 2: The Attitude Towards Sexual Right, Parenting, Non-Reproductive Sexual Behavior and Self-Control According to Age Group Categories (<50 years old and ≥50 years old)

Subscale	Age Category		p
	<50 (n=12)	≥50 (n=15)	
Sexual right	3.7±0.20 (3.3-4.0)	3.6±0.21 (3.2-4.0)	0.7
Parenting	3.5±0.27 (3.1-4.1)	3.5±0.33 (2.9-4.2)	0.9
Non-reproductive sexual behavior	3.5±0.47 (2.4-4.2)	3.4±0.49 (2.5-4.2)	0.6
Self control	3.2±0.64 (2.0-4.2)	3.6±0.82 (1.8-4.8)	0.2

Value in the table: mean±standard deviation (minimum – maximum).

Table 3: Comparison of Attitudes Towards Sexuality of Individuals with Intellectual Disabilities with other Countries

Subscale	Indonesia		Italy [14]	UK [15]				US [16]
	Male	Female	Male	White Western		South Asian		Male and Female
				Male	Female	Male	Female	
Sexual Right	3.7 ±0.31	3.7±0.28	4.3±0.57	4.9±0.60	5.0±0.57	4.3±0.79	4.6±0.70	4.4±0.67
Parenting	3.5±0.32	3.5±0.39	4.2±0.98	5.1±0.76	5.1±0.83	4.5±0.96	4.9±0.90	4.5±0.90
Non-reproductive sexual behavior	3.4±0.70	3.3±0.81	4.5±0.82	5.2±0.66	5.0±0.76	4.4±0.99	4.6±1.03	4.1±0.60
Self Control	3.3±1.12	3.5±1.02	4.5±0.92	4.8±0.79	5.0±0.82	4.2±1.18	4.6±1.03	4.3±0.90

Value in the table: Mean±SD.

White Western and South Asian toward males and females with ID in United Kingdom, and the attitude of young individual who had higher level familiarity (how much contact one may have with individuals) with ID from various ethnicities in United States had been chosen in the comparison [14-16]. White Western British attitude was the most liberal, followed by South Asian British. Italian undergraduate students had similar attitudes with American, they were more conservative attitudes compared to White Western British. More importantly, Indonesian had the most conservative attitudes/negative attitudes towards sexuality in ID.

DISCUSSION

Gender is one of potential factor that may influence the attitude towards sexuality of individual with ID, attitudes toward females with ID was higher compared to males [17]. although some previous studies found inflicting results. This study found that the attitude towards males were similar towards females with ID in all subscales. Even though in general the attitude towards sexuality in ID was less positive, an attitude towards sexual right was the highest compared to other subscales. Although most participants had higher level of familiarity with ID (supporting staff of rehabilitation center, parent representative, and community who were socially engaged with social rehabilitation center), surprisingly, the attitude was still somewhat negative. Negative or conservative attitudes may resulted in some factors i.e. limited access to health information, limited access to sex education programs, knowledge and education, cultural norms, religious beliefs, and familiarity [17-21]. In addition, sexual and reproductive health services toward individual with ID facing with the spectrum of discrimination and exclusion in low and middle-income countries besides their vulnerabilities [9, 22].

Non-reproductive sexual behavior and self-control attitudes were found more negative compared to sexual right and parenting subscales. The statements which were addressing sensitive issues with regards to cultural norms and religious values were more likely related with negative attitudes. All statements (5 statements) in non-reproductive sexual behavior were comprised of homosexuality and masturbation, and 3 statements in self-control were composed of sexual desires and feelings. Catholic and Islam have similar attitudes, norms and values against homosexuality while masturbation was more acceptable [20, 23]. Maintaining virginity until marriage is an important norms and values, thus, sexual behavior expression such as sexual feeling and desire should be regulated. In develop countries, individuals who were sexually active, whether married or not have an access to get contraceptive services in healthcare center to prevent unwanted pregnancy. However, in developing country like Indonesia, sexually active women not married having a cultural and religious barrier and do not have access to get contraceptive services in healthcare center [24]. Intellectual disabled individuals who were financially and mentally independent will face more barriers to get contraceptive services.

Age was an important predictor affecting attitudes towards sexuality, older participants usually had more conservative attitudes compared to the younger participants [25]. However in this study, the attitude towards sexuality in ID was not different among age groups (<50 years old and ≥50 years old). Access to information (television, internet) and the use of social media are influencing individual attitudes towards SRHR including of course individual with special needs such as ID [19]. In the mid-2000s, availability of internet had an enormous impact especially in adolescent. Though, older people gradually changed time by time and spend more time to access media including

internet. With regards of information era in the West and East, internet use and internet user became more prevalent in daily basis. Based on socio-ecology theory, sex-related knowledge, attitudes, and behavior is produced by the interactions between people and their environments including media [26]. Since an information is accessible across the age, the attitudes towards sexuality is similar also across the age.

Although sexuality is a core component of human life, it is often neglected and challenging to individuals with ID. In order to encourage the SRHR, many studies were done to explore the need from individual with ID and community perspectives towards SRHR. Factors that believed as a potential predictor such as gender, age, education background, culture in association with ethnicity, and familiarity with ID had been explored in association with the attitude towards sexuality in individuals with ID. Compared to other develop/high-income countries, Indonesian attitudes towards sexuality was found the most negative. Negative attitudes typically associated with culture and ethnicity in Asian countries [27, 28], while in various ethnics across United States, horizontal-individualism (HI) and horizontal-collectivism (HC) that emphasizing equality were associated with more positive attitudes [16]. Religion is very strong predictor in attitudes towards sexuality in ID, especially many statements are exploring very sensitive issues regarding the religious norms and values that associated with immorality and social judgment [20, 21].

Understanding factors that influencing attitudes towards sexuality is critical especially in Indonesia where the attitude towards sexuality was found negative or conservative because the attitude will directly associated with an opportunity in acknowledging and facilitating their sexual need and expression in society as a human existence. Positive attitude results to more access to sexual health information and services such as sex education programs that will eliminate their vulnerability to sexual exploitation and violence victimization especially in females with ID [29].

LIMITATION OF STUDY

Participants were purposively recruited from population which have engaged with BBRSBG, therefore, although recruited from community they had more thought of individuals with ID. And so, we cannot assume/generalize their attitude from Indonesian general population.

CONCLUSION

Attitudes towards sexuality in individuals with ID is still conservative. Some religious-sensitive statements may affect each subscale and global attitudes. Culture and religious belief are play a role in the attitude towards sexuality in individual with ID. Comprehensive culture and religious-based approach should be developed to advocate the sexual and reproductive health and right of individual with ID.

FUTURE DIRECTIONS

Indonesia is a country with strong religious beliefs and also cultural norms. This study did not incorporate both potential predictor that may have strongly influence the attitude towards sexuality in individuals, more overly, with ID. It would be interesting if we can figure it out the role of religious beliefs and cultural norms in the future study.

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CONFLICT OF INTERESTS

All authors declare there is no conflict of interest

ABBREVIATIONS

ID = intellectual disabilities

ASQ-ID = attitude to sexuality questionnaires towards individuals with intellectual disabilities

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