

Parents' Perception Having Children with Intellectual Disability Providing Sex Education: A Qualitative Study in Yogyakarta

Dwi Karina Ariadni¹, Yayi Suryo Prabandari², Sumarni DW³

¹Faculty of Nursing, Universitas Sumatera Utara, Indonesia

²Department of Public Health, Faculty of Medicine, Universitas Gadjah Mada

³Department of Mental Medicine, Faculty of Medicine, Universitas Gadjah Mada

Corresponding author: Dwi Karina Ariadni

ABSTRACT

Introduction: Children with intellectual disability have the same sexual needs as the average children. Parents are their children's primary sex educators but many parents are afraid of talking to their children about sex. The purpose of this study to explore perception of parents in providing sex education to children with intellectual disability.

Method: A qualitative study using phenomenological approach. Focus group discussion (FGD) and in-depth interviews (face-to face) with ten parents having children with mild or moderate intellectual disability, aged nine-eighteen years registered at SLB Negeri 1 Yogyakarta. Colaizzi method was used to identify core themes and patterns.

Result: Four themes were found: importance of sex education for children with intellectual disability, mother has the most important role in providing sex education, distinction of sex education for children with intellectual disability, religion is important in sex education.

Conclusions: Perception of parents in providing sex education to children with intellectual disability is different from parents with normal children. Parents should be earlier deliver sex education to protect them from sex abuse and the method of giving sex education with practice. The role of parents, especially mother is very important to provide sex education than father.

Keywords: Perception of parents, sex education, intellectual disability children, qualitative study, Yogyakarta

INTRODUCTION

Population Census 2010 shows that the number of Indonesian citizen is

237,6 millions. Among them, 81,4 million or 32,26% has children aged 0-18 years. According to WHO, the number of children with intellectual disability is 7% of the total children aged 0-18 years, which was 5.698.000 in 2010. [1] Based on Basic Health Research (*Riset Kesehatan Dasar*). [2] The percentage of children aged 24-59 months with intellectual disability was 0,14%. This number was only ranked behind quadriplegic (0,17%) and speech impaired (0,15%). The number of children aged 0-18 years with intellectual disability in Yogyakarta in 2013 was 3.507. Among these children, as much as 21% (737) was children aged 0-5 years with intellectual disability. There were 1.227 (35%) and 1.543 children with intellectual disability in elementary school (aged 6-12 years) and aged 13-18 years, respectively. [3] These data shows that most of the children with intellectual disability are adolescent, which usually comes with the needs to meet their sexual needs. In Yogyakarta, there were 748 male and 602 female children with intellectual disability, which have IQ below 70 and have no behavioural adaptation in developmental age. [4] Children under 18 years old with intellectual disability are more susceptible to become victim of sexual abuse compared to normal children. The risk increased to 39-60% and 16-30% for female and male children with intellectual disability. [5]

Information on sexual health is found useful to develop children to have a positive attitude in their sexuality. [6] Sex education covers various knowledge that are useful to

be introduced to children, such as anatomy of reproductive organs, personal sexuality development process, sexual intercourse, reproduction health, contraception, personal image, values, decision making, communication, sexually transmitted diseases, protection against sexual harassment, unplanned pregnancy, and also way to protect reproductive organs in reference to health, hygiene, security and safety. [7-9] Handling of sexual health problems on children with intellectual disability needs collaboration of several parties, including but not limited to parents, teacher, and health care professionals. One of early prevention methods in this matter is giving sex education to children as early as possible by their parents. [10] The role of parents is very important in providing sex education to their children to support them in understanding their sexuality developmental stages and their attitude to their opposite sex. The aim of this study is to explore parents' perception in providing sex education to children with intellectual disability in Yogyakarta.

METHODS

Research place and sample

This study was conducted in Special Public School 1 Yogyakarta Province from Maret 1 to August 1, 2015. This study used a qualitative study with phenomenology approach. Participants were parents (father or mother) of children aged 9-18 years with mild or moderate intellectual disability enrolled in Spesial Public School 1 (SLB 1) Yogyakarta, able to communicate and tell their experiences well in Indonesian language, and willing to sign informed consent. The total participant in this study was ten parents. Participants in focus group discussion were eight mothers. Five mothers and one father in the in-depth interview, three of them were also participate in focus group discussion while the other one were not. All the children in SLB 1 with intellectual disabilities (ie. mild, moderate, severe). There are 79 special school for children with disabilities in Yogyakarta, we

selected participants only from this school because this school only accepted children with intellectual disabilities from kindergarten to senior high school.

Recruitment of respondents

At the beginning of the study, the procedures were explained to the teachers. Then the teachers tell to the parents to joint in this study. If the parents agree, researcher will meet the parents to explain about the study and informed consent was obtained in writing by parent.

Data collection

It is a qualitative, phenomenological research study. In-depth interviews with five mothers and one father. Focus group discussions involving 8 mothers were conducted and purposive sampling was conducted until reaching the saturation level. All the discussions were audio-recorded and later transcribed. Data were collected using semi structured guideline in-depth interview and FGD

Data analysis

Result of the data assessment were classified, after which the main themes and sub-themes were extracted using open code 3.6 B and analyzed using Colaizzi content analysis method.

Ethical consideration

This study was approved by the Ministry of Education and Culture, Faculty of Medicine, Universitas GadjahMada, Medical Research Ethics Committee (MHREC). Permission for the research was issued by the local government of Yogyakarta Region and also granted by the local government of Daerah Istimewa Yogyakarta, Indonesia.

RESULTS

Demographic Characteristics

The total participant in this study was ten parents. Participants in focus group discussion were eight mothers. Five mothers and one father in the in-depth interview, three of them were also participate in focus group discussion while the other one were not.

Table 1. Participation participants in the FGD and In-depth interviews

Parents	Child's name	Age (year)	Sex of child	IQ level
Mother (R1)*	K.J	16	Boy	Moderate
Mother (R2)***	R.M.P	12	Girl	Mild
Mother (R3)***	M.R.S	15	Boy	Mild
Mother (R4)***	P.W.P	13	Boy	Mild
Father (R5)*	P.W.P	13	Boy	Mild
Mother (R6)**	N.A.R	14	Girl	Moderate
Mother (R7)**	B.S.A	11	Girl	Moderate
Mother (R8)**	A.K.R	10	Girl	Mild
Mother (R9)**	A.E.S	14	Girl	Mild
Mother (R10)**	S.M.P	14	Girl	Mild

Information: *In-depth interview; **FGD; ***FGD and In-depth interview

Four Themes Described Parents' Experiences

This study found that there were four themes that described parents' experiences in providing sex education to children with intellectual disability, which were importance of sex education for children with intellectual disability, mother has the most important role in providing sex education, distinction of sex education for children with intellectual disability, religion is important in sex education.

Theme 1: Importance of sex education for children with intellectual disability

"It is not a taboo topic nowadays, normal children should be given know anything, especially children like this, we as parents should be every time given to know" (R1).

"Well, I think it is important, because he will experience it, which is probably earlier for children" (R5)

Theme 2: Mother has the most important role in providing sex education

"Providing sex education is role of parents, mother usually more dominant" (R1).

"Mother plays an important role, because every day, they are often with their mother" (R2).

"The main in providing sex education is mother, then father, then school psychology" (R4)

Theme 3: Distinction of sex education for children with intellectual disability

"Yes, there is the differences, anyway, Normal children delivered once already understood, children like this, we have to delivered every times, every minute should be reminded anyway" (R1).

"I think it is different, because normal child can easily understand while this child needs to see us practicing it" (R4).

Theme 4: Religion is important in sex education

"Yeah, I relate it with fear of sin. As moslem, we are forbidden to hold each other with the opposite sex, except we get married" (FGD participant)

"Yes if you do this (parents give the example to children...) so it is sin, he knows later that can not be repeated again like this" (R1)

"Yes, because we need to have strong belief in our religion, as a foundation in our life. If children don't understand their religion, they could think everything is free for them, no constraints at all" (R2).

DISCUSSION

Based on the result of this study, all parents agree that sex education is important for children with intellectual disability, because in parents' experience, the physical changes in their children during puberty are equal to normal children. This is in line to what Gurol [11] explains in their study, where all mothers, particularly those with sons, concur that sex education is important.

All this time, general perceptions toward children with intellectual disability are they have no feelings and sexual desire, childish, innocent, and unnecessary to have sex education. Therefore, parents often ignorant and sometimes overprotective, since they believe that sex education for their children is worthless. These perceptions were opposed by various literatures that show how children with

intellectual disability experience sexual desires. [11,12]

Every day, children with intellectual disability are often tended by their mother, thus it is normal that they have close relationship with their mother compared to their father. This is similar to what Walker [13] finds that mother has major role in providing sex education to their children. Gurol [11] states that there was different perception regarding this matter, since majority of the mothers agreed that teacher should play major role in providing sex education, not parents. In the interview, the mothers explained that they dismissed the idea of providing sex education since they believed that it was not important, taboo, and they were embarrassed when speaking about it to their children. Balding [14] finds in the study involving 18.000 children aged 11-16 years that the children believed their parents should become their main source of sex education, then followed by teachers and lastly, health care professionals. However, as a matter of fact, the main source of sex education for these children were their friends, not their parents, teacher, or health care professionals.

Parents recognized the importance of good understanding of religion in providing sex education. They explained that it was easier to give sex education after telling the rules in religion. Parents often tell their children that it was sinned to walk around naked after taking a bath, and also improper interactions with their friend with opposite sex, such as hugging. This is in line with what Wilson [10] explains, where there were several parents that used religious teaching or religious community as support in providing sex education.

Parents admitted that with their limited knowledge regarding sexual changes in their children, it was difficult to give sex education or to answer their children's questions about sex, particularly from their sons. [13] Parents stated that they were confused about how to start giving the sex education and the kind of language that was easy to understand by their children. They

realized that the lack of knowledge regarding the sexual development of their children caused reluctance and doubt on how to start giving the sex education. They want to do it properly in the right time. This was difficult for the parents since teaching the children with intellectual disability about daily activities was already difficult, before adding the onus of providing sex education, which made them waiting until their children ask the question about sex first, or sometimes until the children already have specific sex problem. [15] Parents also explained several disadvantages of late introduction of education related to sex and social interaction, which were exhibition of improper sexual behavior by their children, and lack of understanding in their children about how to tend their reproductive organs. [16] The purpose of providing sex education was achieved when the children understand their mistakes regarding sexual behavior, therefore they can protect themselves against exploitation that can disturb their physical and mental health. [12,17-18] Good sex education can help the children with intellectual disability to grow as independent and assertive adults. The children will also develop their social skills, have a positive attitude and healthy sexual behavior, and be less susceptible toward sexual harassment, sexually transmitted diseases, and unplanned pregnancy. [19]

Katz & Ponce [20] states that when giving sex education, it is important to use language that is easy to understand by their children. Most of the times parents must repeat their explanation to their children and confirming it whether or not their explanation is understandable. Parents should also be creative in their explanation to avoid their children feeling bored.

CONCLUSION

Perception of parents in providing sex education to children with intellectual disability is different from parents with normal children. The difference in giving sex education should be frequently repeated and delivered slowly, the method of giving sex

education with practice and parents had spoken about fewer sexual topics with their children. Parents should be earlier deliver sex education to protect them from sex abuse and the method of giving sex education with practice. The role of parents, especially mother is very important to provide sex education than father.

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