

# Understanding of Parents and Adults on the Down syndrome Female Sexual Reproductive Health

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## ABSTRACT

The purpose of this study is to determine the understanding of reproductive health among parents and female adolescents with Down syndrome. This cross-sectional study involved 22 parents and 22 female adolescents with Down syndrome in Kuala Lumpur, Malaysia. The parents were required to fill up the socio-demographic information in questionnaire forms. Scores of parents and female adolescents according to the socio-demographic data, the relationship between the understanding of reproductive health among parents and female adolescents with Down syndrome were determined. The result showing that both parents and adolescents with Down syndrome scored the lowest on sexuality and sexual reproductive awareness. There was a significant relationship between the understanding and awareness of reproductive health among parents and female adolescents where  $r = 0.480$ , and  $p < 0.05$ . There was no relationship between time spent with child and understanding of reproductive health among parents and female adolescents with Down syndrome. Thus Special Education and Occupational Therapy programme on sexual and reproductive health should be part of activity of daily life skills for individual with Down syndrome.

**Keywords:** *Understanding, Parents, Adolescents with Down Syndrome, Reproductive Health*

## INTRODUCTION

Disabled people have sexual and reproductive health needs are the same as others. However, these people often face multiple barriers to getting information and services. This requirement is often overlooked or ignored by disabled people themselves and also those responsible for sexual and reproductive health (WHO / UNFPA 2009). Many people have misconceptions that people with disabilities are asexual and have no sex life (Becker et al., 1997; Anderson & Kitchin, 2000).

As humans, Down syndrome individuals have the right to achieve satisfaction in terms of expressing emotion in his sexuality in ways that conform to our culture (Van Dyke, D.C., McBrien, D. & Sherbondy, A., 1995). Basic Education and Social Reproductive Health Nationality, the Institute for Population and Family Development Countries (LPPKN) health education about sexual reproductive states corresponding to the age teenagers should be taught to all levels of society so that consciousness about reproductive health can be increased. This group intends Down syndrome were not excluded adolescents than health reproductive education. This group requires individual education about reproductive health at the appropriate age and time (Van Dyke, D.C., McBrien, D.M. & Mattheis, P.J., 1996).

The World Health Organisation (WHO), reproductive health is the well-being physically, mentally and socially, and not merely absence of disease associated with the process, function and reproductive system. It is the ability to establish a satisfactory sexual life, safe and free to make a responsible choice. Sexual health is an important component of reproductive health. It is the ability of male and female sexual activity in a responsible and safe whether pregnancy is desired or not. According to Winn, S., Roker, D. & Coleman, J. (1998), there are four interest-related knowledge among adolescent sexuality that is, knowledge is very important for adolescent

psychological adjustment; knowledge is a prerequisite for safe behavior in which teenagers should know how to protect yourself from any threat; understand what is known by adolescents about puberty and sexual development is very important to design and evaluate programs of sex education in schools; knowledge is important because it allows teens to know what is happening in the world of sexuality. Overall, knowledge about puberty and sexuality is an important development for peace and development in a positive and healthy youth.

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The issue of reproductive health including menstruation, pregnancy, contraception, sexually outbreaks of disease, and HIV / AIDS (IFMSA 2008). Reproductive health issues are very focused and reasonable given the primacy of the country's development due to neglect of this issue may involve a very high boarding for care and prevention as the HIV / AIDS (Jariah 2009). With the knowledge of reproductive health, teens will be clear to the reproductive system, knowing their pubic portion, and also able to evade or protect the flogging himself rather than sexual or sexual harassment. Activity of Daily Life (ADL) is a component in one domain under the Occupational Therapy Practice Framework, namely areas of occupation (AOTA, 2008). Sexual activities and menstrual safeguards contained in the "toilet hygiene" is a component in the activity of daily life . This shows the Occupational Therapists play a role in teaching teens about the issue of Down syndrome reproductive health.

## **OBJECTIVES**

The objective of this study was to determine the understanding of parents and young women with Down syndrome on reproductive health, determine the relationship between parents and the understanding of Down syndrome girls about reproductive health and quality of the relationship between the period spent by parents with the understanding of Down syndrome girl about reproductive health. Quality time refers to time spent together in doing something meaningful activities together, such as teaching about personal hygiene. The study is expected to help in providing a better understanding about reproductive health among young women with Down syndrome. Also to enhance public knowledge, especially the guardian or parent of teenagers with Down syndrome on reproductive health issues of adolescents in positive manner.

## **METHODS**

### **The Research Design and Respondents**

This study is a cross-sectional study focusing on young women with Down syndrome and their parents. Sampling method used is purposive sampling. Respondents' parents (n = 22) and the respondent girl with Down syndrome (n = 22) in this study were from various parts of the institution, society, school and center for adults with learning difficulties. Adolescent respondent selection criteria are: the subject is a girl with Down syndrome, aged 10-17 years who have reached puberty, and live with their parents or mother / father. Parent respondent selection criteria are: the mother or the father of the subject. Although the WHO defines adolescents as those aged 10-19 years, this study involved only young women with Down syndrome, aged 10-17 years. This is because teenagers over the age of 17 years may give consent on his behalf to participate in the study. But for teenagers with Down syndrome, they have a degree of intelligence (IQ) that is different and has an intellectual disability. Although more than 17 years of age, they do not necessarily give consent on his behalf to participate in the study Research Ethics Committee, National University of Malaysia, Medical Centre , HUKM ( 2011).

## **The Research Instrument**

Demographic data form molded to obtain background of the respondents. Demographic form for parents to include personal data such as age, race, education level, family relationships, and quality time spent with children with Down syndrome in the day. Demographic data for adolescents with Down syndrome also includes data such as age and age at menarche started. This study used two questionnaires developed by the researchers, the Parent Understanding Questionnaire on Reproductive Health which has eight questions and uses Likert Scale and Questionnaire Understanding Female Adolescent Reproductive Health on the Down syndrome who had nine questions and has a dichotomous choice, namely "Yes" or "No". Face validity of both questionnaires was determined by two doctors and a guard at the Centre for Children with Disability Care Megah Park. Then, a total of 10 occupational therapists who have worked more than two years have examined the questionnaire for content validity index (Content Validity Index). 10 occupational therapists who have evaluated each question in both questionnaires based on the relevance, clarity, simplicity and uncertainty (ambiguity). All comments and suggestions from members of occupational therapy were considered and the content validity index was determined. According to Waltz & Bausell (1981), questions have content validity index will be maintained above 0.75, whereas the content validity index of less than 0.75 will not be used. After the content validity index analysis is done, each question in both this questionnaire has content validity index of more than 0.75. Therefore, all questions will be used in this study. Internal consistency (Cronbach's alpha) for Parent Understanding Questionnaire on the Reproductive Health Survey 0.794 and the Understanding Adolescent Girl About Reproductive Health Down Syndrome is 0.668.

## **The Research Procedure**

While waiting for ethical approval from the Research Ethics Committee of National University of Malaysia Medical Centre (HUKM), researchers find that the center has a teenage daughter with Down syndrome who meet the criteria for study inclusion. Upon approval of the Research Ethics Committee, the researchers sent a letter request permission to conduct research to a few centers with Down syndrome girls.

After getting permission from the director of the center, respondents were selected based on inclusion criteria. Researchers obtain the phone number of the parent to teenage girls with Down syndrome from the teacher and make an appointment with them to answer a questionnaire study. Questionnaires about the understanding of parents and young women with Down syndrome on reproductive health are used. Parents and young women with Down syndrome who understand the purpose of research and agree to take part in the survey as respondents are given a consent form, demographic form and a questionnaire. Consent and demographic forms are filled in before starting to answer questions in the questionnaire form. If the adolescent has a problem when respondents answer questions in the questionnaire, parents can answer on behalf of children. The time required to answer the questionnaire depending on the respondent and no time limit for the questionnaire session.

## **RESULTS**

A total of 22 parents and 22 young women with Down syndrome have agreed to participate in this study. Table 1 shows the sociodemographic data of parents and respondents girl with Down syndrome in this study. Based on respondents aged parents, it was found that the mean  $\pm$  standard deviation age was  $50.73 \pm 6.29$  years. For respondents aged girl with Down syndrome, the mean age was  $13.95 \pm 2.17$  years. Of the 22 respondents were young women with Down syndrome, the mean  $\pm$  standard deviation for age of menarche was  $12:14 \pm 1:55$  those years. In terms of race, respondents in this study a majority of the Chinese nation with a percentage of 59.1%, while the Malays, Indians and others have a percentage of 13.6%, respectively. Based on the level of education, parents found all respondents had received formal education up to either primary, secondary, Diploma, or Bachelor. A total of 59.1% of respondent's parents pursue their studies up to secondary school, 27.3% diploma, bachelor of 9.1% and 4.5% of primary school. Quality control period spent by parents with children, found that the mean  $\pm$  standard deviation was  $1.86 \pm 3:59$  hours.

**Table 1 Features Sociodemographic respondent: parents and adolescent respondents**

<b>Sosiodemographic</b>	<b>n</b>	<b>%</b>	<b>M</b>	<b>SD</b>
<b>Age (years)</b>				
Parents	22	100		
Female Down syndrome	22	100		
Adults				
<b>Age Menarche (years)</b>				
Female Down syndrome	22	100	50.73	
Adults			13.95	
<b>RACE</b>	3	13.6		6.29
Malay	13	59.1	12.14	2.17
Chinese	3	13.6		
Indian	3	13.6		
Others				1.55
<b>Education Level Of Parents</b>	1	4.5		
Primary School	13	59.1		
Secondary /High School	6	27.3		
Diploma	2	9.1		
Degree				
	22	100		
<b>Duration &amp; Quality Time Spent with Down syndrome Adults (hours)</b>			3.59	
<b>Sources of Information About Reproductive Health</b>				1.86
Parents	20	90.9		
Teachers	9	40.9		
Siblings	8	36.4		
Peers	0	0		
Televisyen/ Radio	0	0		
Others	0	0		

Table 2 shows the Understanding Questionnaire score for Parents About Reproductive Health. Scores for each question are generally regarded as ordinal. Score one means 'Do not Know', a score of two means 'Not Sure', a score of three means 'Know little' four score and means 'Very Know'. As a result, it was found that the mean  $\pm$  standard deviation for the total questionnaire score was  $28.82 \pm 3.54$ .

**Table 2 Descriptive analysis of questionnaire scores of parents understanding about reproductive health**

Level of understanding	n (%)			
	1	2	3	4
To what extent.....				
you understanding about the human reproductive system?	1 (4.5)	1 (4.5)	4 (18.2)	16 (72.7)
your understanding of the physical changes in adolescence when they reach puberty?	1 (4.5)	0 (0)	8 (36.4)	13 (59.1)
your understanding about sexuality for teenagers with Down syndrome	1 (4.5)	4 (18.2)	8 (36.4)	9 (40.9)
your understanding of what a sexually transmitted disease?	1 (4.5)	1 (4.5)	7 (31.8)	13 (59.1)
your understanding of how HIV/ AIDS occur?	0 (0)	1 (4.5)	2 (9.1)	19 (86.4)
your knowledge on how to avoid unwanted pregnancy? ( e.g., use of condoms, birth control pills and others)	0 (0)	0 (0)	1 (4.5)	21 (95.5)
your understanding of reproductive health issues such as menstruation, puberty and contraception	1 (4.5)	1 (4.5)	4 (18.2)	16 (72.7)
your understanding of menstruation	0 (0)	1 (4.5)	3 (13.6)	18 (81.8)
Overall Score (M $\pm$ SD) = 28.82 $\pm$ 3.54				
Internal Consistency = 0.794				

Table 3 shows the scores Questionnaire Understanding Down Syndrome Female Teens About Reproductive Health. Each question has a dichotomous choice of "Yes" or "No". Each answer "Yes" is given a score. The sum of all the questions reflect an understanding of teenage girls about reproductive health of Down syndrome. As a result, it was found that the mean  $\pm$  standard deviation for the total questionnaire score was  $5.82 \pm 1.65$ .

**Table 3. Descriptive analysis of questionnaire scores about understanding Down syndrome girls on reproductive health**

Are you .....	n (%)	
	Yes	No
know the physical changes during puberty? (eg wind expansion virgin, pimples, underarm hair, menstruation ...)	14 (63.6)	8 (36.4)
know which part of your confidential member?	21 (95.5)	1 (4.5)
know what can cause you to get pregnant?	3 (13.6)	19 (86.4)
know how to wear sanitary napkins / pads?	22 (100)	0 (0)
know how to properly remove the pads?	18 (81.8)	4 (18.2)
washes the blood impression if exposed underwear?	15 (68.2)	7 (31.8)
know how to take care of personal hygiene during menstruation?	18 (81.8)	4 (18.2)
know how to protect themselves from the unknown man or that other than a family member?	17 (77.3)	5 (22.7)
Overall score (M $\pm$ SD) = 5.82 $\pm$ 1.65		
Internal Consistency = 0.681		

To determine the relationship between parents with Down syndrome girls understanding of reproductive health, Spearman correlation test was carried out. This test shows that there is the relationship between parents with Down syndrome girls understanding of reproductive health, with effect size  $r = 0,480$ ,  $p < 0.05$  (Table 4). Spearman correlation test was also carried out to determine the relationship between quality period spent by parents with Down syndrome girls understanding of reproductive health and the results are showing that not significant relationship.

**Table 4 Correlations between scores of parents and quality period of time spent by parents with Down syndrome girls understanding about reproductive health**

Pembolehubah	<i>rs</i>	<i>p</i>
Scores of parents	.480*	.024
Quality time spent	.078	.731

\*  $p < 0.05$ , statistically Exam - Exam Spearman Correlation  $p$

## DISCUSSION

In this study, only 40.9% of parents who understand about sexuality issues among girls with Down syndrome. According to Siddiqi, S.U., Van Dyke, D.C., Donohoue, P. & McBrien, D.M.. (1999) and Shah, P., Norlin, C., Logsdon, V. & Samson-Fang, L. (2005), there is a misconception among parents and society towards people with disabilities that they have no sexual needs because of disability, there is no risk of being victims of sexual abuse and does not require sex education and reproductive health. Guardian of the female intellectual disabilities need more information about sexual and reproductive health issues such as pain during menstruation, age of menarche, masturbating, eating at around menopause (perimenopause) and reproductive health services free of charge (Lin, L.P., Lin, P.Y., Hsu, S.W., Loh, C.H., Lin, J.D., Lai, C.I., Chien, W.C. & Lin, F.G., 2011). Parents and teachers need to equip themselves with knowledge of sexuality so that they are more confident and prepared to carry out education.

Refer to Table 1, found the main source of information on reproductive health for young women with Down syndrome are the parents (90.9%), followed by teachers (40.9%) and siblings (36.4%). Since parents are the main source of reproductive health information, this study found that the relationship between parents and the understanding of Down syndrome girls on reproductive health (Table 4). This finding is supported by Wurtele, S.K., Kast, L.C. & Melzer, A.M. (1992) in which they brought back the study found that children taught by parents to show progress in skills demand to know the bad touch and personal safety skills compared with children who were taught by the teacher. Their findings also show that children who received sexual abuse prevention education at home and school are more skilled in recognizing a good touch and show the level of personal safety skills higher than children who only receive their education. In contrast, the findings Tegegn, A., Yazachew, M. & Gelaw, Y. (2008) showed that the main source of information on reproductive health is the radio (80.4%), followed by television (73%) and teachers (71.8%). These findings are contrary to their findings because in Malaysia, rarely discussed reproductive health issues through the media. So, parents, teachers and siblings play an important role in disseminating information on reproductive health to adolescents with special needs.

From the study, there were 63.6% of girls with Down syndrome who was aware of physical changes during puberty, such as breast augmentation, pimples, hair in the armpits and genitals, and menstruation. According to Edward (2002) and Panda (2009), it is important for teens to raise awareness of themselves and also important to inform adolescents about body changes during puberty so that they can anticipate and be prepared to change before the change occurs.

For questions that ask about where the parts of the body difficult, this study found a total of 95.5% of girls with Down syndrome know where the parts of their bodies hard. Adolescents with special needs should be taught at, and the names and functions of parts of the hard part. Parents play an important role in introducing the private parts of the body to the child and tell them that is part of the genitalia and should always be concealed from public view (Utusan Malaysia, 2007). Teens should also be informed that the members of the secret can not be touched by anyone in these parts like the liver and can only be touched in certain circumstances eg for cleaning purposes .

Next to the question asking about how to protect themselves from men who are not known or that other than family members found about 77.3% of girls with Down syndrome who know how to protect themselves from men who do not know. This question is more focused on whether young women away from men with Down syndrome who do not know if the man known to approach or avoid contact of the unknown man. This is because most children with Down

syndrome are warm and friendly with others. Many parents of Down syndrome girl respondents in this study said their children will not approach strangers but very close to the man who is a member of the family.

Refer to Table 3, there were only 13.6% of girls with Down syndrome who knows how a woman becomes pregnant. This question had the lowest score among the eight questions in the questionnaire about Understanding Female Adolescent Reproductive Health. Most respondents knew girls with Down syndrome babies in the wombs of pregnant women but do not know how a woman becomes pregnant. Qazi study (2003) conducted in Pakistan showed 66% of girls know how a woman becomes pregnant. However, they do not clear the actual process of pregnant women. In the study of Jain & Khanna (2006), most young women do not realize that menstruation will stop during pregnancy. Lack of knowledge about how a woman becomes pregnant is because parents often have difficulty discussing sexuality with their children (Greydanus & Omar 2008). Knowledge about how a woman's pregnancy and what caused the pregnancy is important for young women with Down syndrome to prevent sexual abuse and unwanted pregnancies occur. With the knowledge about sexual and reproductive health issues, youth will be clear and conscious acts of others who do not properly dispose of themselves and will have the skills and strength to say no when faced with this situation.

From the study, showed that all respondents of Down syndrome girls know how to wear sanitary napkins (100%). A total of 81.8% of girls with Down syndrome know how to properly dispose of pads, 68.2% wash their clothing if exposed to blood and 81.8% of girls with Down syndrome who know how to take care of personal hygiene during menstruation. Parents tell young women with Down syndrome need a reminder to take care of personal hygiene during menstruation such as changing pads, sanitary napkins with remove the paper and wash the blood stains on clothing with soap. Many young women with Down syndrome just wash the blood stain on clothes without using soap. This is supported by the Social Biology Resource Centre (1990) which states adolescent intellectual disability need a reminder to change the pads. According Scola & Pueschel (1992) and Kaur et al. (1997), with appropriate guidance, a girl with Down syndrome can manage personal hygiene during menstruation. Their findings were supported by Edward (2002) which states most girls with Down syndrome are able to manage menstruation. Teaching about personal hygiene during menstruation is important to people with Down syndrome because they are unaware that personal hygiene is not right will cause self-smelly, uncomfortable and likely to get bacterial infection in the genital area (Social Biology Resource Centre 1990).

## CONCLUSION

In conclusion, the study found that parents and young women with Down syndrome have the knowledge about reproductive health, but is not comprehensive. Adolescents with disabilities including intellectual disability youth not immune from sexual problems. Personal safety is a key point emphasized by parents and teachers of children with special needs. Therefore, these people should have access to information about sexuality, contraception, sexually transmitted diseases and a variety of topics related to safe behavior. Sexual and reproductive health education as a whole should be part of educational programs for individuals with Down syndrome. Level of individuals with Down syndrome have cognitive and learning styles differ, this learning process should be done on an individual basis based on the understanding and needs profession of occupational therapy intervention emphasizes a holistic and comprehensive form, then in the process of dealing with activities of daily living such as dressing, eating, toileting and social participation, an occupational therapists should focus on care menstruation and sexual activity of a client, especially for teenagers with special needs. In addition, occupational therapists also play a role in disseminating information on sexual and reproductive health to adolescents with special needs.

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