

What, When and How to Learn About Sex: The Narratives of Students With

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ABSTRACT

Sex education program among youth with disabilities is pertinent to their overall physical, emotional, health and well-being. However, due to its sensitivity and taboo, the topic is rarely addressed in the Malaysian context. The aim of this study is to explore the understanding about sex among disabled youth and how teaching sex education among disabled students can be improved. To obtain meaningful data, a qualitative interview was conducted. Six students, ages from 20-27 years old, with various disabilities including impaired vision, impaired hearing, physical disability and autistic were recruited via the snowball sampling technique. Thematic analysis was employed to analyze data. The results show that all participants agree that sex education is important. They believed that sex education is essential as a tool for prevention from sex-related diseases and ensure their sexual safety. It appeared that the participants prefer health personnel and disabled educators Disabilities to deliver the subject in a more casual manner and on one-to-one basis. The participants also reported that disable educators will make them more confident to communicate and share their sexual concerns and they feel more cared. Finally, learning about sex through the covert way has led to some confusion. Therefore, parents, teachers and health personnel should provide appropriate avenue, knowledge and resources to discuss about sex with disabled children similar to their non-disabled friends.

Keywords: *Disability, health, sex education, youth, well-being*

1. INTRODUCTION

Every individual is born with his or her sex regardless of having any intellectual disabilities (ID) or development disabilities (DD). However, people with disabilities are commonly seen as 'asexual' and they were denied to have sexual desires like anyone else. They have been regarded as inhuman, asexual or childish (Swago-Wilson, 2008) or that they were over fond of sex and that they could not control their sexuality (Child Statistic, 2009). But those with disabilities also have sexual needs and desires like normal healthy individual. In fact, many young adults with ID are sexually active, or have strong intentions to become one (McGillivray, 1999). Unfortunately, individual with ID/DD have not been provided the same opportunities (Boehning, 2006; Cabe & Cummins, 1996) and access (Hamilton, 2002) to learn and make decisions about sexuality as the other developing peers.

Instead of being allowed to properly develop sexual behaviors, their sexual expressions are unconsciously prevented, and social education is not provided for them. These attitudes have resulted in limited access to sexual

health information and exclusion from sex education program (World Health Organization [WHO], 2011). The myth and misconceptions are not only denying individual with ID/DD to get access to sexuality education, but also affect these individual to lead a fully autonomous and having a fulfilling life inclusive of their sexuality.

In relation to unwanted pregnancies, sexual abuse and other sexual high risk situations among those with ID/DD shows an urge and need to implement a formal sexual education for them. This is because, people with ID/DD are prone to physical, psychological and sexual abuse (McCarthy, 1996; Robinson, 2010). As a matter of fact, individuals with disabilities are at a three times greater risk of sexual abuse than other individuals (Reiter, Bryen, & Schachar, 2007; van Berlo et al., 2011). Plus, many of them will not disclose because they are afraid of not being believed, and others are unable to do so due to the physical or emotional limitations imposed by their disability (Bedard, Burke & Ludwig, 1998).

Lack of sexual knowledge, relationship experience and protection skills (Tang & Lee, 1999) may increase the risk of abuse and impair the ability to recognize an experience as abusive (McCarthy & Thompson, 1997; Murray & Powell, 2008; Tharinger, Horton & Millea, 1990). Therefore, this study attempts to examine the understanding about sex among student with disabilities. This research is pertinent specifically in education and disability studies in general because how sex is learnt and understood is greatly shaped by the social and cultural norms of a particular community.

2. METHOD

Researching a sensitive issue, like sex, requires careful selection of methods and consideration of the approach needed. Renzetti and Lee (1993) have identified four areas in which research is more likely to be sensitive than others: a) research into the private sphere or personal experiences, b) study on deviance and social control, c) areas that invade the vested interests of powerful persons or the exercise of coercion or domination and d) research upon or “into” sacred things. This research fits into the first identified area as it involves discussing disable students’ personal experiences with sex which may in part be unpleasant and embarrassing.

For this study, qualitative methodology was deemed more appropriate and is most often chosen by researchers who undertake research on sensitive topics (McNamara, 2001; Mohamad Diah, 2014; Bute et al., 2017). This is principally because of its strength in providing rich textual description of people’s experiences in a given situation. Qualitative methodology according to Punch (1998) may also help researchers to identify behaviors that contradict beliefs, opinions and emotions from the participant’s perspective. Moreover, the flexibility inherent in qualitative research helps the researcher to understand meanings, interpretations and subjective experiences of vulnerable groups (Liamputtong, 2013).

In addition, qualitative methods allow researchers to listen to ‘voices of the silenced, othered, [and those] marginalised by the social order’ (Liamputtong 2007:7). This study employed an open-ended approach which allows participants to speak about their feelings and experiences using their own words rather than to follow a set of pre-determined questions that are usually employed in a survey research.

Participants

In order to obtain relevant data for this study, six disabled students from a public university were recruited via the snowball sampling. Four of them are males and two are females. The respondents have different type of disabilities: autistic, impaired vision, impaired hearing and multiple disabilities. They are single and are currently completing their studies in various disciplines

like Social Sciences, IT, Religious Studies and Economics. Their age is between 20-27 years old. All of them are Malays and holds the Person with Disability (OKU) card. Five respondents attended the mainstream school. Only one attended the special needs school.

Data Collection Techniques

Interview is a popular tool to access people’s experiences, attitudes and feelings about many social issues in the society. There are three types of interviews according to Fontana and Frey (2005): structured interviews, semi-structured and unstructured interviews. This study employed unstructured interview to obtain data. This type of interview exposes researchers to unanticipated themes and help them to better understand research participants’ perspectives (emic) about a particular phenomenon.

The researchers developed unstructured interview to elicit understanding on sex education, including sources and access to information, experiences with masturbation and menstruation, sexuality, barriers to sex education and suggestions for improving the subject. The interview protocol was based on previous studies on sex education and disabled students. In addition, the researchers also collected information concerning age, educational level, ethnicity, marital status and type of disability. All interviews were transcribed and thematically analyzed.

3. FINDINGS AND DISCUSSION

Finding(s)

Based on the analysis, this study has revealed three important themes. Firstly, sex education is seen as important and appropriate subject to be taught in secondary school as a means to prevent disabled students from getting any sex-related diseases as well as to ensure their sexual safety. Secondly, selected persons only are entrusted to teach the subject in a more casual manner and on one-to-one basis. The participants also reported that disabled educators will make them more confident to communicate and share their sexual concerns. This, makes them feel more cared. Finally, learning about sex the covert way continues among parents. Thus, it has led disabled students to some confusions. This section is organized according to these themes.

An appropriate subject in school

Most of the respondents expressed that sex education is important particularly to students between 13-18 years old. At this age, the right information must be delivered so that sex-related problems could be prevented. Zaki, impaired hearing recalled his experience in school:

“I learnt about that sex thing with friends. My friends and I laughed and made jokes about it. We’re not sure of the accuracy of the information. When we listen to stories that students at our age

do that ‘wrong thing’ like early age pregnancy, have sex, boys behave like girls and others, I think we need to be informed more about it. The problem with sex is REAL!”

On the other hand, Ali who is physically disabled said: “I used to masturbate for pleasure during my high school. I don’t know much about the implications of doing it to my health. I only discovered after I entered university. Now that I know, I want to lead a healthy life.”

Nevertheless, sex education is less exposed to students in a different school setting. For instance, Khalid who is visually blind, recalled his own experience while studying in a religious school:

“I learnt only about religion in the *ma’ahad* (religious school). I’m not exposed to information pertaining to sex. I know a little bit about sex from friends, but it was on the surface. I read on newspaper students are being molested by teachers. How is this possible? How can we protect ourselves? What can we do to stop this? Somebody must tell us this in school”.

Diana believed that teaching sex education is more than acquiring knowledge only. She said:

“Aside from informing students about the do’s and don’ts, the subject should tell students that sex comes with responsibilities. For instance, managing pregnancy, raising children, childbirth and others.”

Qualified persons

Most respondents agreed that teaching sex education in schools needs qualified persons by which they mean health personnel. Interestingly, the female respondents have suggested that only doctors and nurses can teach the subject. Nadia, a physically disabled student has been campaigning through the social media about sex-related issues. As a comprehensive sex education activist, she shared issues like safe sex, menstrual hygiene management (MHM) and many more. She said:

“Sex education is about creating awareness of what you can do if something happened to you. I would prefer doctors or nurses to teach the subject. I trusted them more because they deal with real cases. They know better than others”.

Her view is supported by Diana who has similar disability:

“I prefer doctors to deliver the subject. Doctors understand how our body works, what we should do or should not do. If I want to conceive or go for family planning, the doctor should advise me so that I will not do more harm to my body”.

Consequently, the male respondents suggested a different person to teach the subject. The qualified

person may also include the disabled teachers themselves. As Ahmad who is autistic mentioned:

“This is a sensitive subject to be taught in school. Therefore, the best person who should teach must be among us (disabled). He or she understands our needs and concerns. We can express our feelings better because we speak the same language”.

Similarly, Khalid shared his concern too:

“Teaching sex education to blind students is different. We use our touching senses more. Perhaps abled-bodied teachers are not comfortable with this. We need disabled teachers who has a different skill set”.

The covert way

Interestingly, none of the respondents mentioned that parents should take up the responsibilities to teach their children about sex. To them, parents are less accommodative compared to friends. Many instances have shown that parents did not talk about sex directly. For instance, Nadia, her mother usually used kias (analogy) to explain about sex-related things. She said:

“Our conversation about this topic is normally very brief. My mum try to avoid talking about this most of the time. Sometimes I’m confused with what she’s trying to say”.

This is also true for other disabled students where parents used different terms in their conversation. Khalid mentioned:

“I find it is easier to talk about this with my friends. They are more open to discuss about this. Parents are not so helpful. Whereas teachers, they are less flexible. Neither here nor there, they are helping us to understand this topic. I’m frustrated. Our generation (Gen Y) is different. We need them to help to understand this topic .”

In short, the above responses indicated that sex education has a huge role in the life of the disabled students. It is not merely knowing what it is but what to do and how to react.

Discussion(s)

Due to cultural and religious mores, many traditional societies including Malaysia has a very restricted notion about sex education. Even if sex is discussed in a formal way, such as in the biology subject, any aspects of sexuality are omitted from the learning process to conform to the cultural and religious restrictions. Sex is taboo and discussion about it is generally regarded as obscene or dirty. Most parents (in this case Malay parents) in general do not talk openly about sex in front of their children or discuss with their children the issues relating to sex or bodily functions, for example as a preparation for puberty, the teenage years or marriage.

Children are expected to experience these transitions for themselves, but of course while these things are not spoken of in an overt way, children must learn about sex and bodily processes in some fashion. In most instances, information about sex and issues related to it is passed on by friends who are older or the nearest kin, other than the parents.

In Malaysia, sex-related issues are not well explained in science subjects as part of the biological process which affects both abled and disabled persons' reproductive capacity. It is notable that overt discussion about sex, even something that is more oriented to bodily changes, is avoided, even between mothers and daughters. Thus, much information about sex is learned in a very covert way. Another way of explaining knowledge about sex is to say that it becomes a kind of tacit knowledge that is not openly acknowledged, but nevertheless, is understood in a very informal way. Interestingly, the respondents in this study obtained information about sex from their friends. This is somewhat ironic given that all of them are unmarried.

Sexual education has received many perceptions from each and every level of community which become a great challenge for its implementation. In addition, people with disabilities often has limitation in both intellectual functioning and in adaptive behavior, which includes conceptual, social, and practical adaptive skills (Schalock et al., 2012; Schalock et al., 2010). This negatively influences attainability of knowledge and skills that are beneficial for good sexual health. This shows that people with disabilities need to have a comprehensive and practical sexual program specific for them.

Additionally, sexual education helps disabled students to understand about sexual protection which result in healthy sexual relationship, help in family planning and prevent any unplanned pregnancy among women with disabilities. Those who received family planning information were less likely to experience an unintended pregnancy than those who did not receive such care. By having a good understanding of sexual education, this will help them to avoid complications during pregnancy and have good access to prenatal care. It is important that sex education contents should include relevant skills too aside from giving knowledge regarding how to do something.

Teaching sexual education to students with disabilities requires slightly a different set of approach compare to the abled-bodies. The lack of training or guidance to educators involve with disabilities people also pose a barrier and challenges to sexual education program. Ideally, the training should be prepared by experts with sufficient expertise in the field especially when involve with the disabled persons. Inadequate guidance, or training may result poor information given and may results in ineffectiveness of the program. As a consequence, these choices ultimately depended on the

individual teacher's judgement on what would be appropriate to teach considering based on time available, the age of the learners and the local norms about sexuality and sexuality education. This result in great variations with regard to the content being taught and how it is taught both within and across schools.

Murphy and Young (2005) mentioned that a comprehensive sexual education empowers individuals with ID/DD to enjoy personal sexual fulfilment and act as a protection from any sexual abuse, unplanned pregnancy or sexually transmitted diseases. Learning about sexuality and their body prepares them for changes related to their sexual development like menstruation, wet dreams or being aroused. It aids them to independently take care and in charge of their body. This include a practical information about self-care of menstrual hygiene, dressing skill, knowledge of growth spurt and sexual function as well as coping skill to face this changes. Information like understanding emotions and impulses, self-image, assertiveness, attraction and interpersonal relationships are also important to those who are at pubertal age. Therefore, is it important to implement a good sexual education to students with disabilities. However, considerations must be made in order to modify the sexual program to allow for information to be understood and learned in a way that is easy and practical to them.

4. CONCLUSION

Today, many of us do not acknowledge that most people experience sexual feelings, needs, and desires, regardless of their abilities. As a result, many young people, including those with disabilities, receive little or no formal sexual health education, either in school or at home. In addition, sexual education is very important to help them to be mentally prepared with their emotional, physical and social changes.

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