Sex Education and its Importance in Children with Intellectual Disabilities

Zihinsel Yetersizliği Olan Çocuklarda Cinsel Eğitim ve Önemi

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SUMMARY

Sexual identity is an individual being aware of his/her sexuality and acting in a manner appropriate to it. With or without intellectual disability, every individual is born with his/her gender. For centuries, it was thought that individuals with intellectual disabilities were inhuman, asexual, or childish, or that they were over fond of sex and that they could not control their sexuality. However, these individuals were perceived as such because they did not know where, when and in which situations sexual behaviors were appropriate. In other words, they could not control their sexual behaviors. Just like healthy individuals, those with intellectual disabilities also have sexual needs and desires. Sex education starts at birth. It continues until reaching adulthood or beyond. Parents are the best guides for all children, either those with intellectual disability or not. The most accurate information about sex, which is an issue when there are conflicting messages from different sources, should be first provided by parents. There is no suitable model of sex education for all children with intellectual disabilities and information should be appropriate to the child's level of understanding. Those with intellectual disabilities are more at risk of sexual abuse than others in society and for this reason, it is important to adopt a multidisciplinary team (doctor, nurse, midwife, psychologist and social services specialist e.g.) approach towards the sexual health of the intellectually disabled. The most accurate information sharing about sex depends on good communication between families, schools and individuals, and by receiving professional support when needed. This review emphasizes the importance of sexual education for children with intellectual disabilities and the role of nurses in sexual education.

Keywords: *Children; intellectual disability; sex education; sexual abuse.*

ÖZET

Cinsel kimlik, kişinin cinsiyetinden haberdar olması ve cinsiyetine uygun davranışlar göstermesidir. Zihinsel yetersizliği olsun ya da olmasın her birey cinsiyeti ile doğar. Yüzyıllardır zihinsel yetersizliği olan bireylerin aseksüel, çocuksu, cinsellikleri kontrol edilemeyen, insanca olmayan, bağımlı veya sekse aşırı düşkün oldukları kabul edilirdi. Oysa bu bireyler, cinsel içerikli davranışların nerede, ne zaman, hangi durumlarda uygun olup olmadığını bilemedikleri için, yani cinsel içerikli davranışlarını kontrol edemedikleri için böyle algılanmaktadırlar. Sağlıklı bireylerde olduğu gibi zihinsel yetersizliği olan bireylerin de cinsel gereksinimleri ve arzuları vardır. Cinsel eğitim doğumla beraber başlar. Aile ve toplum içinde erişkin yaşına hatta ölüme kadar devam eder. Zihinsel yetersizliği olsun ya da olmasın tüm çocuklar için en uygun danışma kaynağı ebeveynlerdir. Değişik kaynaklardan çelişkili mesajların verildiği cinsellik konusunda en doğru bilgilendirmenin öncelikle aileler tarafından yapılması gerekmektedir. Cinsel eğitimin tüm zihinsel yetersizliği olan çocuklara uygun bir modeli yoktur. Çocuğun anlama düzeyine uygun bilgiler gereklidir. Zihinsel yetersizliği olan bireyler cinsel istismar açısından toplumdaki diğer bireylerden daha fazla risk altındadırlar. Bu nedenle bu bireylerin cinsel sağlıklarına yönelik multidisipliner ekip (doktor, hemşire, ebe, psikolog, sosyal hizmet uzmanı gibi) yaklaşımının benimsenmesi önemlidir. Cinsellikle ilgili en doğru bilgi paylaşımının, aile, okul ve bireyler arasında kurulacak iyi bir iletişimle etkili olabileceği, gerektiğinde profesyonel bilgi desteği alınarak yapılmasının önemi dikkate alınmalıdır. Bu derlemenin amacı; zihinsel yetersizliği olan çocuklarda cinsel eğitimin önemini ve cinsel eğitimde hemşirenin rolünü vurgulamaktır.

Anahtar sözcükler: *Çocuk; zihinsel yetersizlik; cinsel eğitim; cinsel istismar.*

Introduction

Sexuality is not only a need, but also an instinct that is frequently unavoidable. Since the beginning, individuals have tried to govern their sexuality both to control their reproduction and to enrich their lives.[1] Regardless of having any intellectual disabilities, every individual is born with his/her sex. Sexual identity is being cognizant of an individual's own sexuality and showing appropriate attitudes to it.[2] Sexuality is a fundamental need and an inseparable part of the personality of every individual, regardless of being female, male or child.[3] The sexual development of a child is a natural part of his/her general development.[4] It is a multifaceted process that is closely associated with basic human needs such as being loved and accepted, feeling love for others and showing his/her love, feeling desired and attractive, sharing his/her emotions and thoughts. It includes not only anatomical and physiological process, but also sexual knowledge, beliefs, attitudes and values.[5,6] Depending on their mental development levels, the sexual development of children and young individuals with intellectual disabilities follows the same stages as children with normal development more slowly and depending on their mental development.[2,7] Therefore, individuals with intellectual disabilities face certain adaptation problems in this process. Their sexual urges, desires and fantasies are similar; however, their way of discovering and expressing feelings about sexuality is less acceptable for individuals with

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intellectual disabilities because of their dependence on others, restricted living conditions and limited social opportunities.[8] The fact that individuals with intellectual disabilities also have sexual rights is usually forgotten, and their needs for sexual knowledge, emotions and thoughts are neglected.[2]

When it comes to sexual education, the names and functions of body parts and the mechanics of reproduction come to mind. Sexual education should, however, be more comprehensive and meaningful. Sexual education includes an individual's understanding of physical, emotional and sexual development, the development of a positive concept of self, a respectful attitude towards other individuals' rights, opinions and behaviors, and positive behaviors and value judgments.[2]

For centuries, individuals with intellectual disabilities have been regarded as inhuman, asexual or childish,[9] or that they were over fond of sex and that they could not control their sexuality.[10] However, unwonted sexualized behaviors can occur because the individuals do not know whether their sexually oriented behaviors are appropriate in terms of place, time and context. In other words, they cannot control these behaviors.[11–13] Individuals with intellectual disabilities have the same sexual needs and desires as healthy individuals.[14] For these individuals, marriage and having children can represent the sexual life of normal adults to which they aspire.[5] The aim of this compilation is to emphasize the importance of sexual education for children with intellectual disabilities and the role of nurses in sexual education.

Individuals with Intellectual Disabilities and Issues of Sexuality

Intellectual disability is a term that includes the deficiency of social and personal competence necessary for behaviors known as cognitive skills and adaptation function. There are varying levels of intellectual disability. According to DSM-IV-TR, the degree of intellectual disability is divided into mild, moderate, severe and profound. Approximately 85% of individuals with intellectual disabilities have mild intellectual disability (IQ level 50 to 70), 10% of them have moderate (IQ level 35 to 50), 4% have severe (IQ level 20 to 35), and 1–2% have profound intellectual disability (IQ level <20).[15]

Mild intellectual disability cannot be detected generally until after first or second grade at school. By the end of adolescence, they will generally have an academic achievement at the level of sixth grade. Most children with moderate intellectual disabilities can acquire adequate conversation and communication skills in early childhood. Generally, they have difficulties academically and do not usually exceed second and third grade levels. In adolescence they find it hard to socialize. They spend little time with others and can benefit from intensive social and occupational support. Individuals with severe intellectual disabilities can develop communication skills in childhood; however, they can learn important words at any time. Children with profound intellectual disabilities can learn certain self-care skills, but they require appropriate education to learn to communicate.[15]

The fact that individuals with intellectual disabilities also have sexual rights is usually forgotten, and their needs regarding sexual knowledge, emotions and thoughts are neglected.[2] Instead of being allowed to develop proper sexual behaviors, their sexual expressions are unconsciously prevented, and social education in this respect is not provided for them.[10] Therefore, inappropriate sexual behaviors observed in these individuals arise from lack of knowledge or being restricted as to the expression of their sexuality.[8] Moreover, compared to their peers with normal development, it is more difficult for intellectually disabled adolescents to acquire the right information about sexuality to provide competence for social interactions. Therefore, they are devoid of opportunity for expressing their social and sexual interests properly.[16]

Sexual education begins with the birth of individual. It continues until adulthood or beyond.[2] Regardless of having intellectual disability, the most appropriate guide for all children is their parents. Because contradictory messages can come from different sources, the first and most accurate information about sexuality should come from the parents.[13] Every individual requires continuous sexual education appropriate to his/her age to develop positive attitude to his/her own sexuality.[17] Asking about sexuality from an early age constitutes the most important part of sexual education. The most important point for all questions asked about sexuality is the parents' attitudes while answering these questions. In this case, the child should not be blamed, scolded or reduced to silence. Being blamed or scolded gives the child the impression that these questions should not be asked, leaving him/her to resort to observing and performing experiments, as well as searching for answers by asking other individuals In this way sexual education moves beyond the parents' control and may go in unwanted directions.[2]

Every family wants to provide their children with sexual education in accordance with their family structure and culture.[2] Many parents, however, become flustered and embarrassed, or anxious when sexuality is mentioned. They give evasive answers or refrain from answering at all, distracting their child's attention to safer areas.[4] In a study conducted with the parents of children with Down syndrome by Pueschel and Scola (1988), 70% of parents found it disturbing to talk with their children about sexuality.[18] However, children perceive non-verbal behaviors and evasive answers and learn to associate conversations about sexuality with feelings of embarrassment and anxiety.

It is important to use age-appropriate language and pro-

vide information that child can understand.[4] Moreover, parents of children with intellectual disability stated that they have difficulty using graphical descriptions and the special anatomical terms which are necessary for children to understand sexual activity.[19] Some were concerned that sexual education might increase their child's sexual behaviors.[8] Others felt that there was no need to give their intellectually disabled children sexual education because they presumed that their children were asexual.[20]

Sexual Education for Children with Intellectual Disabilities

There is no appropriate sexual education model for all children with intellectual disabilities. Individualized education should be provided that is appropriate to the child's comprehension level. For example; a child with moderate intellectual disability can require more basic knowledge in comparison to a child with mild intellectual disability. This knowledge can include differences between male and female, types of good and bad touch, how to behave in different social settings.[17]

When giving sexual education, it is essential to determine the child's development level and impart information in accordance with it. The sexual development of children with special needs follows the same physical stages as with other children; however, in terms of mental development it lags behind and follows the stages more slowly. These children have difficulty comprehending themselves and others with regard to sexuality. They can be angry because they do not know what to do when they become sexually aroused. It should be taken into consideration that these children, whose behaviors change in adolescence and who become angry and annoyed, can be aroused sexually. These children have difficulty in following social cues and can ask questions which are inappropriate to the environment. They can be unaware of the fact that they should control their sexual urges, resulting sometimes in public masturbation. Therefore, it can be thought that they have greater sexual interests and show more sexual behaviors in comparison to their peers. These children need to be taught where, when, and in which situations, sexual behavior is appropriate. Because of their learning disability, it is crucial to repeat sexual education at regular intervals and to reinforce with examples in accordance with their developmental levels.[21,22]

The questions of children with intellectual disabilities about sexuality should be taken seriously like those of every child, without criticizing them or using words such as "shame", or "forbidden." Critical approaches impede the education of all children. The questions asked by these children can be incompatible with their chronological ages. For example; an adolescent female with moderate intellectual disability can use sentences such as "My breasts grew," "I am going to pee," etc., in public. In such cases, people should be patient and tell the child that what she has said is inappropriate to the environment and time, and tell her again how to behave in public. Instead of becoming depressed, panicked or angry, or punishing or shouting at the child, in such cases it is crucial to know how to approach the child and provide her with education, considering these behaviors as an experience. Problems cannot be resolved with such attitudes; on the contrary, they are intensified. The child cannot understand why you yelled at him/her. His/her inappropriate behavior should be prevented by distracting him/her, and it should be explained, in a manner appropriate to his/her cognitive level, that his/her behavior is wrong and how he/she should display appropriate behavior. It should not be forgotten that sexual education can avoid and reduce these problems and help in finding solutions.[21]

For those with mild intellectual disability, as with children in general, it is possible to control behaviors with sexual education. The sexual development and sexual urges of individuals with moderate intellectual disability can be controlled with support and education. Individuals with severe intellectual disability have difficulty comprehending social rules and showing appropriate behaviors. They are unable to control their sexual urges.[22]

Sexual education of children with intellectual disabilities should include the following information:

- Developing social skills including general and special terms
- How to develop and maintain different types of friendship
- Coping with problems and rejection in friendships.
- Sexuality and relationships including parenting and marriage
- Preventive behaviors
- Physical and emotional transformations during adolescence
- Sexual biology including reproductive organs
- Appropriate and inappropriate sexual expressions
- Sexually transmitted disease
- Safe sex
- Contraception
- Masturbation etc.[17]

In relation to the sexual education of individuals with intellectual disabilities there are several erroneous concepts.[3] These include;

"Sexual education is not important for individuals with intellectual and developmental disabilities." Comprehensive, life-long, and individualized sexual education has crucial importance for all individuals in developing healthy self-esteem and personal relationships. Sexual education enables individuals with intellectual and developmental disabilities to protect themselves from sexual violence and abuse, unplanned pregnancy, and sexually transmitted diseases.

"Sexual education prompts individuals with intellectual and developmental disabilities to show sexual behaviors." Sexual education given to these individuals enables them to make healthy decisions about sexuality.

"Individuals with intellectual and developmental disabilities do not comprehend sexuality." Humans are sexual beings, and individuals with intellectual disabilities also want to express their sexuality. If sexual education begins from an early age, in accordance with their cognitive development levels, and continues in a life-long manner, children with intellectual disabilities can learn appropriate sexual behaviors (e.g. not masturbating in public).

"There is no sexual education program for individuals with intellectual and developmental disabilities." In other countries it is claimed that there are sufficient sexual education programs for individuals with intellectual and developmental disabilities; however, most of these education program have not been adequately evaluated.[3] There are no sexual education programs for individuals with intellectual and developmental disabilities in Turkey.

The Importance of Sexual Education in Preventing Sexual Abuse of Children with Intellectual Disabilities

Individuals with intellectual disabilities are at a three times greater risk of sexual abuse than other individuals.[9,14,23–25] The prevalence of sexual abuse of these individuals varies from 25% to 83%, and it is foreseen that more than 90% will experience some form of sexual abuse over the course of their lives.

Individuals with intellectual disabilities are more vulnerable due to a variety of reasons, such as generally being dependent on adults for their care, social isolation, excessive protection, the lack of other people's awareness of these individuals' sexual requirements, misconceptions leading to the suppression of their healthy sexual and psychosocial development, the lack of education about sexuality and sexual abuse, and being considered socially insignificant.[25,26] As with all humans, they react positively to the interest and love shown to them.[26] However, due to an inability to judge a situation, they can accept quietly any sexual offer or intimacy without realizing that they can be exploited sexually.[13]

Because individuals with intellectual disabilities have generally fewer friends and have difficulty making new friends, they have a strong desire to satisfy the friends they have; increasing the possibility for their exploitation. Adolescents in particular are more open to exploitation because they value their friends more. In order to maintain their close relationships with their friends, these individuals may not recognize negative behavior by their friends or may tolerate sexual abuse behaviors.[26]

It is crucial to take into consideration that these individuals do not have a vocabulary by which to identify the sexual parts of the body and their functions. It is difficult for individuals who have limited or no knowledge about sexuality to identify the events that they experience, or to notice that the exploitative behavior is wrong.[26,27] Studies reveal that these individuals have less knowledge and experience about sexuality, show more negative attitudes towards sexual activities, and have a tendency to experience sexual abuse more often.[28–31] Moreover, children with intellectual disabilities who suffer from sexual abuse tolerate the abuse and refrain from revealing it due to communication difficulties, feeling guilty, fear of being abandoned, the possibility of being excluded from their family, and being unloved, as well as being accepted and rewarded by the perpetrator.

When all factors about sexual abuse are taken into consideration, the fact that children with intellectual disabilities are not provided with education about sexual health and protection from sexual abuse, or they are provided with this education after the abuse is experienced, constitutes the fundamental basis of the problem.[26] Females are at high risk of getting pregnant and both females and males are at high risk of sexually transmitted diseases (HIV, AIDS).[10,32,33] Thus, sexual education is an important determinant, positively affecting social and behavioral skills,[34–36] decision-making skills[37] and knowledge.[38,39]

For these reasons, the education of parents with children with special needs is even more important than that of parents with children with normal development. Parents of children with special needs should be informed about the developmental differences in these children and how to educate their children within the family. The family should be included in the sexual education of children as in their education in other fields. It is also crucial that society in general is made more aware of this subject.[21]

The Role of Nurses in Sexual Education of Individuals with Intellectual Disabilities

The sexual education of children with intellectual disabilities is essential for their protection against sexual abuse, preventing the risk of pregnancy and sexually transmitted diseases. Nurses play a crucial role in ensuring the safety of these

children and keeping them healthy.[40] Within the scope of their duty, authority and responsibility, child and adolescent psychiatry nurses especially, are responsible for determining and meeting the education and counseling requirements of the child/adolescent and his/her parents.

Nurses working with children with intellectual disabilities can significantly help these children develop their social responsibilities and sexual behaviors by means of evaluation, education, arrangement of service procurement, proper guidance and regular follow-up.[7,8,41,42] A nurse's support includes offering genetic counseling for parents with children with intellectual disabilities, conducting studies on protecting and developing their health in the scope of early initiative programs for children with intellectual disabilities and making suggestions for legal regulations.[43] Moreover, the adoption of a multidisciplinary group (including doctor, nurse, midwife, psychologist, social service specialist etc.) approach that is solution-oriented towards the sexual problems of individuals with intellectual disabilities is also crucial. Furthermore, the most accurate knowledge sharing can be effected through good communications among family, school and individuals, with professional support if required.[13,44]

Conclusion

Because of misconceptions about the sexuality of individuals with intellectual disabilities, this group is not being provided with sexual education. However, it is known that those with intellectual disabilities are at greater risk of sexual abuse. When these individuals are not informed about sexuality, they have difficulty identifying their experiences and perceiving that exploitative behaviors are wrong. In addition to providing this information as a precautionary measure to prevent sexual abuse, remedial interventions are also needed. Also, in order to protect these individuals from sexual abuse, nurses, who play a key role in protecting public health, should, in cooperation with other health professionals, enable them to receive sexual education in accordance with their developmental levels.

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