

CASE REPORT

Therapeutic and Ethical Dilemma of Puberty and Menstruation Problems in an Intellectually Disabled (Autistic) Female: a Case Report and Review of the Literature

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Received: 08 Nov. 2013; Accepted: 28 May 2014

Abstract- Intellectual disability is a term used when a person has certain limitations in mental functioning and skills. Autism is a group of developmental brain disorders, collectively called autism spectrum disorder (ASD). Teenagers with learning and physical disabilities are more likely to have menstrual problems compared to the general populations. The parents of a 12-year-old girl with autism spectrum disorder and intellectual disability referred to the coroner due to her numerous problems of puberty (menstruation) including: poor hygiene and polluting herself and the environment, not allowing to put or change the pads and changes in mood and physical health prior period, requested for the surgery (hysterectomy). In legal medicine organization after reviewing the medical records, physical exams and medical consultations with a gynecologist and psychiatric, surgery was not accepted. Hysterectomy (surgery) due to the age of the child, either physically or morally is not recommended. The use of hormone replacement therapy has side effects such as osteoporosis. In these cases, it seems noninvasive methods (behavioral therapy and learning care skills) under the welfare experts is also more effective and morally.

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Acta Med Iran 2015;53(10):663-666.

Keywords: Intellectual disability; Menstruation; Autism; Hysterectomy

Introduction

Intellectual disability means that an individual has special disabilities in mental functioning and in skills including communicating, social skills, and taking care of her or himself, and social skills. A child with such disabilities may be slower than normal child in learning and developing (1).

Physicians have determined some factors that result in intellectual disabilities. Genetic, Problems at birth and during pregnancy, and Health complications (2).

An intellectual disability is not an illness. It is not contagious. In addition, it's also not a mental disease, such as depression. No treatment is considered for intellectual disabilities. Although, most children with these disability can learn to do many things by spending more time and by more effort than typical children (1).

Autism or autism spectrum disorder (ASD) is a group of developmental brain disorders. The word "spectrum" is related to the wide range of signs, skills,

and impairments, or disability that children with ASD may suffer from. Some children are slightly impaired by their signs, while some are severely disabled. The exact reason of autism spectrum disorder (ASD) is not clear, but it seems that both genes and environment play significant roles (3,4).

Autism is a complex, behaviorally defined, static disorder of the immature brain (5).

"Handling the girls menstrual problems with disabilities represents a challenging medical dilemma. However, not all adolescents with disabilities will face with problems (6).

Scientists clarify that menstrual problems in girls with disabilities are most of the time unique to the population and may lead to an important disruption to their lives. The most prevalent problematic menstrual symptoms include hyperactivity, impatience, aggression, enhanced agitation, and self-mutilation. Teenagers who have problem in learning and physical disabilities are more probable to have menstrual problems in

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comparison to the normal population (7).

Girls with autism spectrum disorder (ASD) will get their periods similar to normal developing girls. A girl may need the help and support of her mother to adjust to and handle this great physical change. One of the main milestones is her first period. ASD doesn't affect when girls start their periods (8).

The pubertal development of disabled adolescents are slower compared to the normal population and thus they are more isolated, but they are as sexually experienced as them. The sexual development of physically disabled adolescents' and their requirements for sex education and guidance should not be ignored. Physically disabled girls are at risk of sexual abuses and exploitations and more attention is needed to protect them (9).

Finding the reason for intervention and the exact aim of treatment are the most vital matters regarding use of interventions to change menstrual flow in adolescents with disabilities. Reasons for intervention may associate to unusual bleeding of uterine, hygiene, fear of pregnancy, mood issues, and acute onset of other medical conditions. Goals of treatment include a reduction in the amount of bleeding, periodic amenorrhea, or treatment of signs, like mood issues or dysmenorrhea. Primary treatment options must be safe, minimally invasive, and nonpermanent (10).

The decision of treatment has to rest on a multidisciplinary team, alongside the girl and her parents or caregivers, who should be given the opportunity to know available management options and the advantages and disadvantages of each. Managing the menstrual problems of girls with disabilities represents a challenging medical dilemma (6).

In this specific case (an autistic girl), we challenge which treatment is better? Behavioral therapy and learning care skills, Medical (using drug) or surgical.

Case Report

The parents of a 12-year-old girl with autism spectrum disorder and intellectual disability referred to the coroner due to her numerous problems of puberty (menstruation) including: poor hygiene and polluting herself and the environment, not allowing to put or change the pads and changes in mood and physical health prior period, requested for the surgery (hysterectomy). In legal medicine organization after reviewing the medical records, physical exam and medical consultations with gynecologist and psychiatric, surgery was not accepted, the result was: Hysterectomy

(surgery) due to age of the child, either physically or morally is not recommended. The use of hormone replacement therapy has side effects such as osteoporosis. In these cases, it seems noninvasive methods (behavioral therapy and learning care skills) under the welfare experts is also more effective and morally.

Discussion

For an adolescent with either physical or developmental disabilities and her caregivers, menstruation could be a significant challenges. The hygiene component of irregular early bleeding episodes and the behavioral issues which associate with menstrual periods particularly in developmentally delayed adolescents can cause major problems. Moreover, issues related to sexuality and vulnerability to abuse and pregnancy increase parental concerns. Information about puberty, menstruation, sexual activity, safety and the capacity to consent to any sexual act must be evaluated. Teenagers with disabilities are believed to be asexual, but they are sexually active as much as other teenagers and are at higher risk for forced sexual encounters. In case of lack of information, suitable education on hygiene, infections that are transmitted sexually, contraception, and measures for prevention from abuse must be provided. Most teenagers those can use the toilet without help can learn to use pads or tampons properly (10).

Education of the teenager girls should be appropriate to their level of understanding and clear clarification of hygiene issues, and suitable behavior may be required. Families can find more support from other caregivers in comparable circumstances or health care professionals experienced in the day-to-day care of teenager girls with learning disabilities helpful (11).

There is no flawless strategy to suppress menstruation in mentally retarded girls. Girls should be permitted to go through puberty before any effort is made to halt periods. The different therapeutic choices have diverse side effects, and the therapy needs to be appropriate to the adolescent's specific clinical situation concerning weight, bone mineral density (BMD), thromboembolic risk factors, mobility, and understanding. There is a need for a more complete discussion of this problematic matter and a crucial requirement for researchs in this area to scrutinize the effectiveness of therapeutic interventions, opposing effects, psychological profits, and harms, and patient and family opinions (11).

The surgical methods of contraception “hysterectomy” considered for sterilization of mentally retarded females. Most of the time sterilization is used to protect those female from pregnancy as a result of rape and to manage menstrual periods. This act had its advocates and adversaries (12).

Laws in many countries permit the sterilization of those found to have severe intellectual disabilities. The Parliament of the Egyptian was unsuccessful in including a provision of preventing the use of sterilization as a “treatment” for mental illness in its patient protection law (Mental Health Law, 2009). Number of 15 states of the United States, have laws that do not protect mentally retarded females from involuntary sterilization. Throughout the world, women with disabilities are violated in their right to decline sterilization (12).

In the Islamic religion, hysterectomy for mentally retarded females is forbidden if there is no medical necessity since this could be dangerous for them, as mentioned by Mohamed AlKhalileh the Secretary-General of the Department of Fatwa (13). He also mentioned that Islamic religion enforces the family of mentally retarded girls to take care of them and protect them from danger and harm and give them all their rights like normal children, (Jordan Now, 2013) (12).

According to the UN Human Rights (2008) The Convention on the Rights of Persons with Disabilities delivers a basis for upholding the rights of individuals with disabilities and comprises particular articles about involuntary sterilization. Article number 23 emphasizes the right of individuals with disabilities to found and maintain a family and to preserve their fertility. Article number 12 confirms the right of individuals with disabilities to recognition everywhere as individuals before the law and to enjoy legal capacity similar to others, such as access to the support they may need exercising their legal capacity. Article number 25 obviously expressed that free and informed consent should be the basis for providing health care to individuals with disabilities (12).

In a study by Diekema (2003) have shown that involuntary sterilization obviously characterizes a violation of the principle of respect for autonomy if done contrary to the wishes of patients with mental retardation who gave them right to make decision about sterilization (14).

Violence against women with disabilities can range from neglect to physical abuse to denying them even the traditional roles of marriage and childbearing (15).

Physicians, the courts, parents and caregivers need to

be aware of the latest medical and surgical options available, the currently applicable laws in each state if such exist, and the ethical guidelines to determine what treatment option is in the best interests of the patient (16).

Available literature supports the teaching of self-care skills to clients who have severe and profound intellectual disability. Although some programs have been developed to deal with menstrual management for women with mild and moderate intellectual disability (17).

For parents, teachers and service providers it is important to know that a patients with ASD improve physically and sexually the similar to normal individuals. Patients with Autism wish to express their sexuality. They have the right and the choice to do it. They can express their sexuality individually or in a relationship (either heterosexual or homosexual). It is essential for children and young people with autism to be aware of their bodies, puberty, hygiene, and sexuality (18).

In our Islamic society, we attention to performing justice and prevent any assault to Intellectual disabled females. We emphasize both individual and social benefit and make decisions about each case separately due to the range of IQ, physical ability, social and cultural level of the family and perform ethical principles. This review emphasizes that care needs to be individualized. "The decision of treatment has to rest on a multidisciplinary team consists of gynecologist, psychologist, and forensic specialists and based on Islamic and ethical law in legal medicine organization, the result was: Hysterectomy (surgery) due to the age of the child, either physically or morally is not recommended. The use of hormone replacement therapy has side effects such as osteoporosis. In these cases, it seems noninvasive methods (behavioral therapy and learning care skills) under the welfare experts is also more effective and morally.

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