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Chapter 21

DOWN SYNDROME AND SEXUALITY

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ABSTRACT

In recent years important gains and changes have been observed in the life of teenagers with Down syndrome (DS) with increased inclusion into society. This chapter will discuss adolescence and sexuality in teenagers with DS from a descriptive study of 50 patients with DS between the ages of 10 and 20 years. The mean age was 13.5 years, 50% females. 86% went to school with 62.2% in school for over six years. Of the patients that attended school, 60% went to special education school and only 10% read and wrote correctly. In evaluation of autonomy, 66% took shower, 78% performed their physiological needs, 77% intimate hygiene and 76% oral hygiene without help. 42% affirmed being able to do anything that is asked; 22% perform all tasks in the home; 10% felt they were incapable of doing anything and 4% used public transportation without help. 42% of the teenagers masturbated, 24% on a daily basis, 75% in private, and 25% in a public location. 42% had already kissed at a mean age of 12.9 years, mean age of the partner 16.1 years; 26.8% of these partners had DS. 82% found themselves attractive and 33% would not change anything in their appearance. We found that they presented normal development in the exercise of their sexuality, but with important difficulties in their autonomy and difficulties in school, needing careful interventions in order to make

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their social interaction the best possible. Their pubertal development was normal and they were satisfied with their body image with future perspectives of working, finding a partner and living a normal life getting married and having children.

INTRODUCTION

Teenagers with Down Syndrome (DS) need to be prepared for a life of limitations and possibilities. Important gains and changes have been observed in relation to these individuals and society in general is increasingly accepting and allowing their inclusion into community roles. The public is tending to see this deficiency as a natural diversity within humanity and with the advancement of the treatments devoted to chronic illnesses the life expectancy has greatly increased. Health professionals are now confronted with a new reality to provide health services for teenagers with DS and the challenge of adapting to the needs of these young adults.

As the care to special needs of these adolescents with intellectual disability improves, their quality of life improves as well, and at the same time that integration within a community structure offers great advantages, it should not be forgotten that there are also more risks, liberties and responsibilities. Therefore, during childhood and especially adolescence, it is necessary that they develop self-awareness, the ability to choose, criticize, and stimulate their own autonomy, to prepare for work, questions and acts about sexuality.

It is essential to remember that sexual desire is ever present, independent of the degree of mental/intellectual impairment. This discussion is usually handled with prejudice and discrimination, especially when dealing with patients with DS, causing various controversies. These young adults present a variety of manifestations in relation to sexuality and reproductive health, reflecting their stage of development, their experiences and circumstances of their lives. Masters and Johnson [1] also discussed the importance of recognizing that individuals with mental deficiencies differ in their ability in learning, independence, emotional stability and social abilities.

It is in this context of fear and uncertainties that health care providers (HCP) can help the teenager to develop. Often, the family is unable to answer all of the questions proposed by these individuals, offering answers that are many times incomplete or wrong. Therefore HCP should assume the role of counselor and friend, providing the necessary advice and guidance to his/her parents.

In this particular group, questions regarding sexuality (including pregnancy and contraception) are often overlooked. Several studies have demonstrated that in severely compromised patients, where social exile and negative self-image makes sexuality difficult, their actual sexuality is not different from common individuals. Sexuality is always present and may be expressed in its affective component (the feeling of good will), erotic (desire, excitement and pleasure) or affective-erotic (the association that provides a more genuine relationship).

The title of 'mentally deficient', almost entirely used indiscriminately, masks the differences and peculiarities of each case. Despite the fact that they differ in their learning capacities, independence, social stability and outlook on sexuality, almost all are able to understand some level of sexual knowledge and social behavior. The more compromised DS

individuals have problems that are more centered in questions of hygiene and self-care, making it necessary most of the times, for example, to reduce or prevent menstrual flow.

There are still many beliefs and taboos in relation to the mentally challenged, ranging from being asexual to overly sexual and these people are often times treated as if they were children. The majority of the families assume an over-protective role, seeing and caring for these individuals as if they were infants and asexual. For the teenager with some type of mental limitation, the expected and progressive independence from the parents is delayed or even absent. Therefore, it is necessary that the process of transferring responsibilities should have its own rhythm for each teenager, for each family and for each limitation, with emphasis on communication and on encouraging the teen to occupy his place within society. It is up to the health professional that works with these patients to assist them, as well as their families, in the process of reaching a maximum degree of independence. Family members, HCP and teachers sometimes underestimate the abilities of these individuals, believing they will never become sexually active.

Mental deficiency alone does not determine sexual behavior. Despite the social isolation that many teenagers with DS face, studies have shown that many of these teens would like to have a sexual life, get married and have children. These teenagers have fewer opportunities to live with their peers, making it difficult to achieve their life goals. The probability of these individuals becoming isolated from society is high, in turn leading to difficulty or inability to find partners. "Different" adolescents are excluded or may feel excluded, therefore, as a way to overcome these differences and barriers, they may assume behaviors that could be of risk, each time greater, such as sexual activity without being prepared or with insufficient protection or even nonconsensual. For this teenager, sexual relations may signify being attractive, loved, chosen, even if affection is not involved.

The health professional should assist these young adults and approach their questions in a clear and objective manner, providing the conditions for the exercise of a healthy and safe sexual life. In addition to understanding the sexual possibilities, discussions and orientations for the challenged patient and their family in relation to sexuality, the HCP should also point out the vulnerabilities these patients have (in light of their diminished capacity of self protection, victims of sexual abuse). From childhood, these individuals should understand healthy attitudes that should be taken in relation to their bodies. If integration within the community is offered, they will need orientation regarding abilities and appropriate attitudes of social behavior. It is necessary to emphasize the importance of shedding light on sexuality and contraceptive measures for these teens, their parents and educators in an individualized fashion or through educational programs [2].

The information regarding sexuality should include: relationships with others in a social context, information about the differences between genders, physiological and psychological understanding about sexual development and orientation regarding adequate social behavior. According to Elkins and Haefner [3], conversation concerning normal physical development and how to avoid sexual abuse should always be approached and Blum [4] argued that when caring for the mentally challenged, it is of utmost importance that instructions be provided about hygiene, menstruation, masturbation, STDs/AIDS, contraception and marriage. This author also discussed [4] some common beliefs concerning mentally challenged teenagers that in time has been *proven to be wrong*, like the following statements:

- Teenagers with deficiencies are not sexually active

- The social and sexual aspirations of the teenager with deficiencies and chronic illnesses are different from that of their peers
- The parents of teenagers with deficiencies provide sufficient sexual education
- Teenagers with chronic illnesses are sexually vulnerable
- Problems in relation to sexual expression are because of the chronic disease
- Individuals with chronic diseases are not satisfied with their appearance.

In a review [5] it was concluded that the pubertal development of individuals with DS is similar to that of other adolescents. Hormonal studies in proved that the hormones responsible for sexual maturation of women with DS were equivalent to those of women in the general population, with the age of the first menstruation approximately 12.5 years, while in normal women around 12.1 years. It was also shown that women with DS had regular menstrual cycles.

Pueschel and Scola [6] questioned the parents of children with DS about their perception in relation to their children's social interactions, interest in the opposite sex, sexual function and sexual education. They discovered that 40% of male teenagers and 22% of the female teenagers masturbated. Over half of the teenagers showed interest in the opposite sex and had social aspirations. Therefore, the HCP has a fundamental role since, many times, he/she is the only reference in the sexual orientation of this population and because of this, it is necessary to create space within the medical consultation, where the HCP can approach and discuss aspects about sexuality, give information about contraceptive measures and alert the patient to the risks and prevention of STDs.

One of the fundamental aspects for developing social skills is helping the teenager understand, in full, their limitations. Awareness and acceptance of this syndrome may cause suffering to the teenager and their parents, but are essential for the full development of their potential and the reformulation of their life goals given the limitations imposed.

OUR STUDY

Our study was a cross-sectional study of 50 teenagers with Down Syndrome aged between 10 and 20 years, who attended the multi-professional DS clinic of the Department of Pediatrics of the Santa Casa de São Paulo. A structured questionnaire was used, applied by the researchers along with the teenager with DS after authorization by the adolescent and his/her caretaker.

The age of the teenagers ranged between 10 and 20 years, with a mean of 13.5 years; 64% were younger than 14 years, 50% were of the male gender. 86% were enrolled in school and 62.2% were in school for over six years, 4.7% in an all day long setting. Of those who went to school, 73.3% were enrolled in public schools, 40% in traditional schools and 60% in special education schools. 28% of the teenagers considered themselves alphabetized, with only 38% being able to write their names. 10% read and wrote correctly and 6% read and wrote functionally. In analyzing the functionality of these teenagers, it was found that most were able to function independently, see table 1.

Of the 25 female teenagers evaluated, 26% had already menstruated, with a mean age of menarche 11.5 years. 18% knew the date of their last menstruation, the flow was regular in 56.6% and the majority (56%) were responsible for their intimate hygiene.

Of all interviewed, 36% affirmed knowing what sexual desire was and 50% described already having felt sexual desire. When questioned about masturbation, 18% described knowing what it is and 42% answered that they frequently masturbated with 24% doing so daily, 75% in private locations and 25% in public locations. Regarding kissing, 42% affirmed that they had already kissed, being that 85.7% were simple lip kisses. The mean age for the first kiss was at the age of 12.9 years and the mean age of the partner during this first kiss was of 16.1 years. 28.6% of these partners also had DS and only two teenagers had kissed more than three partners. Of all interviewed, 18% had already dated, with 1/3 having relationships with other DS patients.

Table 1. Autonomy in the daily activity

Shower Physiological needs		Intimate hygiene	Oral
		hygiene	
Autonomy 66%	78%	70%	76%
With help 24%	12%	22%	14%
Totally			
dependence 10%	6%	8%	10%
No answer -----	4%	-----	-----

One 18 year old female teenager had sexual relations with a 15 year old partner, yet did not respond as to whether or not he had any syndrome. 34% answered that they had been given education about sexuality and that the majority (70%) were oriented by their parents. However, only 18% had discussed sexual issues with their parents and the same percentage said they discussed sex in school.

In relation to future goals of these teenagers, 58% said they intended to work, with 20.7% wanting to be teachers. When questioned about marriage, 56% showed interest and 52% intended to have children. Most subjects also showed good self-esteem, see table 2. A curious answer was given by a female teenager, saying that if she could, she would rather not have DS. Most patients were satisfied with themselves, see table 3.

Of these teenagers, 82% demonstrated aptitude in helping with tasks in their home, with the most often performed tasks related to dishes (washing, drying, putting them away) and with general cleaning (making the bed, putting away objects). On the other hand, 66% did not perform any activity outside their homes, 73% went to the grocery only for small purchases. 70% performed leisure activities: 57% of these performed some sporting activity, 20% went to parks, and 20% went to the theater and movies. 43% of those who performed leisure activities were authorized and did so by themselves. The great majority (88%) went to parties and social events. When openly questioned about what they felt capable of doing alone, 4% affirmed that they were able to do anything that is asked; 22% felt that they were capable of performing tasks of the home, 10% responded not being able to do anything and 4% were able to use public transportation without help.

Table 2. Appearance

Good looking	82%
Bad looking	2%
No answer	16%

Table 3. What would you change about yourself?

No answer	43%
Nothing	33%
Hair	
Shoulder/arms	4%
Stomach	4%
Not aware	2%
Foot	2%
Having Down syndrome	2%

DISCUSSION

If adolescence is a period of challenges and confrontations for the teenager with normal cognitive abilities, these problems can be much greater for the teenager with Down syndrome (DS). Teenagers with mental deficiencies live varying degrees of social isolation, limiting the opportunities for interaction and affective involvement that are a part of learning and sexual discovery and makes living with this disease harder. Many of these teenagers do not have the capacity to respond to the demands of their environment or own will of independence. Among the teenagers evaluated, we discovered that a great majority had been in school for a significant period. However, they had significant deficiency in learning, with only 10% being able to read and write correctly.

Concerning future perspectives of the teenagers, partially 1/3 intended to work, the majority wanted to get married and have children, demonstrating life projects, despite the great dependence they face today. On the other hand, 2/3 did not perform any activities outside their homes, confirming great dependence. It is important to emphasize that mentally challenged individuals are not similar in their learning capacity and independence, emotional stability and social abilities, yet most are capable of learning and developing some social abilities. Patients with DS with severe deficiency generally have difficulty with hygiene and self-care. Behavior training programs, such as intimate hygiene methods for the women present good results in teenagers with mild or moderate deficiencies. Siemaszko et al [7] in studying the menstrual history of teenagers with DS found that only 44% were autonomous as to menstrual hygiene, 44% needed some type of help and 12% were totally dependent.

During puberty, the teenagers are faced with an ever changing physique, and for them body image is very important and as they make themselves attractive, desired and normal. Teenagers with DS frequently have unique features, which may be a risk factor for the development of difficulties in social adaptation and is even harder, when living in a society that gives such importance to body image. Merrick et al [5] found the mean age for first menstruation at 12.5 years; regular flow in the majority, which was also found in the present study. Goldstein [8] and Siemaszko [7] also did not find differences in studying the menstrual

histories of teenagers with DS, while Evans [9] found the first menstruation to be 13 months later in patients with DS.

Teenagers with DS present an ample variety of manifestations in relation to sexuality and reproductive health, depending on pubertal development, on their experiences and familial and social circumstances. When evaluating the interests of teenagers with DS in the exercise of sexuality, it was found that over half of the adolescents demonstrated interest in the opposite sex. When questioned about masturbation, 18% answered that they know what it is and 42% answered that they frequently masturbated and of these, 24% did so on a daily basis, which is compatible with findings by Pueschel and Scola [6]. Another consequence of social isolation for these teenagers is the fact that they receive less information regarding sexuality, reproduction and conception. Parents, teachers and doctors do not feel comfortable discussing this theme, which impedes the patients from having adequate sexual education. Castelao et al [10] evaluated patients with DS and the health team that cared for them and discovered that the parents saw their offspring as eternal children and were afraid that they assumed a sexual life, because of the risks. Health professionals are also not prepared for the orientation of the exercise of sexuality in these adolescents. In our study, 34% of the teenagers received education about sexuality, and the majority (70%) received such education from their parents. However, only 18% had discussed sex with their parents and the same percentage discussed sex in school. Parents should be educated in relation to the existing taboos, so that in an integrated fashion and without contradiction, they can work with their children about sexual issues in a comfortable manner. They need to actively participate in the process, providing the space to expose their doubts and ask questions [11].

All of these issues indicate the necessity for sexual education for patients with mental deficiencies, and the objective should not only be the use of condoms or birth-control pills, but also the actions and attitudes of these teenagers, evaluating the particular limitations of each [12]. Teenager with DS, like other adolescents, need to express their feelings in an appropriate manner. Sexual repression can alter their internal equilibrium, lowering the possibility of psychological wellbeing. When well discussed, sexuality improves affective development, facilitating relationships, improving self-esteem and the integration within society. The information should always be repeated and have long-term attendance in order to guarantee the success of this learning process. Whenever possible, dramatization and audio-visual material should be stimulated.

Thus, for their greater social inclusion, such patients should undergo early interventions by multidisciplinary teams, so that their development and social interaction are the best possible.

CONCLUSIONS

Teenagers with DS:

- Have normal feelings of sexuality
- Have significant difficulties in their autonomy and difficulties in school, needing careful interventions in order to make their social interaction the best possible
- Their pubertal development was normal

- Are satisfied with their body image
- Have future perspectives of working, finding a partner and living a normal life, of getting married and having children.

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