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CLINICS AND PRACTICE

Living as a couple with Down's syndrome

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Abstract

The improvement in the living conditions of individuals with Down's syndrome has opened enormous opportunities to lead a normal life and take advantages of projects in keeping with their expectations and hopes. The integration into schools and workplaces, participation in the community, and an independent life are the scenarios that have enabled them to study, work, have friends, a partner and, occasionally, their own home. The emancipation from their families is still exceptional, but is a challenge that culminates in a voluntarily chosen life project. The most usual tendency is that they live indefinitely with their families until these die and then go on living with another family member or in an institution. For many of them it is unthinkable to live alone, form a partnership or have sexual relationships.

But, what do individuals with Down's syndrome want? As members of our reality, they want the same as other young people: to have a job, a partner, a home and to be able to live together. In some cases these wishes have received the support of the families, who with a certain amount of risk and bravery, have offered them the opportunity to form their own family unit and enjoy a normal life with the necessary support. This article is drawn from the real and daily experience of 14 years of supporting the emancipation process of these individuals who have started to live together as a couple and a family.

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PALABRAS CLAVE

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La vida en pareja con el síndrome de Down**Resumen**

La mejora de las condiciones de vida de las personas con síndrome de Down ha supuesto enormes oportunidades para normalizar sus vidas y gozar de proyectos acordes con sus expectativas e ilusiones. La inserción escolar y laboral, la participación comunitaria y la vida independiente son los escenarios que les han permitido estudiar, trabajar, tener amigos, pareja y, en ocasiones, su propia casa. La emancipación de sus familias es todavía excepcional, pero supone un hito que culmina un proyecto de vida elegido voluntariamente. La tendencia más habitual es que vivan indefinidamente con sus padres hasta que estos fallezcan y luego vayan a vivir con otro familiar o a una institución. Para muchos es impensable vivir solos, que formen parejas o que tengan relaciones sexuales.

Pero ¿qué quieren las personas con síndrome de Down? Como miembros de nuestra realidad, desean lo mismo que todos los jóvenes: tener un trabajo, una pareja, una casa y poder vivir juntos. En algunos casos estos deseos han recibido el apoyo de las familias que, con ciertas dosis de riesgo y valentía, les han ofrecido la oportunidad de que se constituyan como una unidad familiar propia y gocen de una vida normalizada con los apoyos necesarios. Este artículo se nutre de la experiencia real y cotidiana de 14 años apoyando los procesos de emancipación de estas personas que han iniciado su convivencia como pareja y familias.

Love and affectivity in the person with Down's syndrome

Many authors agree in that the vital and existential importance of love is a determining factor in our physical and emotional well-being, our happiness, and satisfaction. There are biological, evolutionary, socio-cultural and psychological approaches that help us to understand the universality of love, the adaptive function of sexual conduct, the social differences and the various forms of human behaviour.

Most of the literature on sex-affectivity and disability place the accent on the medical, educational and sexual conduct aspects, avoiding the affective territory. The affectivity of individuals with a disability is no different from other human beings: the conditions in which they live (limited social environment, over-protection, lack of opportunity or restrictive environments) will be the reasons that prevent them from enjoying an amorous and dignified sex life.

The low social inclusion, the excessive dependency, infantilisation, and the lack of recognised adult roles are obstacles for a satisfactory sex-affective development. For this reason the educational task should not only be focused on learning and promotion of cognitive abilities, but also on the promotion of psycho-affective development of social abilities and maturity.

Sexuality and disability

The World Health Organisation (WHO) defines sexuality as "a central feature of human beings, present throughout their lives. It covers sex, identities and gender roles, eroticism, pleasure, intimacy, reproduction, and sexual orientation. It is experienced and expressed through thoughts, fantasies, desires, beliefs, attitudes, behaviours, practices, roles, and interpersonal relationships. Sexuality

may include all these dimensions, but not all of them are always experienced or expressed" (WHO, 2006).

Sexuality is inherent in human beings and it becomes apparent very early. Its appearance in young people with Down's syndrome causes a lot of anguish and triggers very diverse reactions. The difficulty is not so much in their own sexuality, but in its acceptance by their environment.

The incidence of social abilities

We do not talk about intimate relationships without taking into account the personal relationships that are established. The limitations of social abilities (lack of knowledge of social canons, poor management of the conventions, communication difficulties, lack of discretion...) has a lot to do with a lack of community participation or with not exercising a social role than the disability itself.

We cannot demand independence if we encourage dependence or that it is treated differently and in forms of acquaintances, family, close friends or strangers, if we do not correspond with different styles of relationships in each case. We cannot expect the use of social conventions if they are not educated for this. They will not have adult relationship patterns if we perpetuate treating them as children. It is also important to avoid the many homogeneous, dependent and restrictive rules and styles.

The socialisation of an individual with a disability takes place in all the environments in which he/she takes part: the family, friends, work, the neighbourhood, society. Some have an occasional incidence and others will discover the richness of social relationship.

Before starting a couple relationship

Before we establish if individuals with Down's syndrome may have a satisfactory sex life, we should make some

observations. If the sexuality does not only refer to coitus, but has something to do with attraction, desire, with the capacity to establish a stable relationship, being in love, being protective, and has a continuing plan: How does someone with Down's syndrome fall in love? Perhaps, it may be difficult to integrate these aspects, but we must admit that the limited social and family support does not help in the understanding and handling of couple relationships.

We have observed indiscriminate infatuations, imitation behaviour and "random courtships" that do not have a real consistency. It is often tolerated that they explore couple relationships, but without consolidating them or consummating them. They are couples who cannot sleep together, who are never alone in a room, but can hold hands or give a loving kiss with restrictions.

We know some couples "induced" by their families that have a good relationship and pair off their children without them having chosen to. We also see families that boycott a relationship because they do not accept the social-familial environment of the couple. These manipulations are also attempted in the general population, but individuals with a disability do not have the means to protect themselves.

The choice of partner has some very concrete expectations and personal identifications. We know people who reject falling in love with someone with the same condition, they prefer someone without a disability or with one different to theirs. Individuals who tell us that "they have met someone special that does not have the syndrome or anything, and only has epilepsy and works in a special workshop". In these cases we observe the rejection and denial of their own identity.

On other occasions, social inclusion favours the possibility of falling in love with someone without a disability. This situation causes much suffering, although it is resolved very naturally. Once again normality favours personal development.

Despite all these obstacles, people with Down's syndrome choose partners, fall in love and desire them. And when desire appears, inevitably, the alarm sounds. The reactions of their environment can be: frightened, denial, not give it importance or suppress it. We have cared for young people who have been emotionally decompensated after a sexual relationship (not necessarily coitus) due to not being mentally prepared on the one hand, and on the other by the terrible feeling of guilt experience after the environmental rejection received.

Feelings and sexuality are very serious and respectable aspects. We do not want social exclusion and at the same time to avoid relationships because they cause us distress. There are families who tolerate the affection but not the sexuality, and this leads to couples with the same consideration as infatuations appropriate to pre-school age.

Access to a real and satisfactory couple relationship involves the experience of the disability itself. It is important to know it, accept it, accept the reality, accept the difficulties, and expect rejections to achieve aims.

Consolidation of the couple as a family

The consolidation of the living together of two people as a couple is socially recognised as the creation of a new family

unit. It entails its members agreeing to the appropriate organisation and functions in order to be able to be differentiated from the respective families of origin.

This process is built by establishing daily habits: schedules, weekend activities, celebrations and holidays, telephone calls, preservation of personal information, etc.

At the beginning there is an excessive presence of the families. The individual with Down's syndrome does not have the strength to place limits on the protective instinct of the family, and for this reason, is able to give excessive accommodation to parental wishes. These couples usual end up becoming appendices of their families of origin, without their own functioning. Almost certainly, their families will not help in this independence process of the couple, as they have doubts on the abilities of their children to manage their daily lives or have little tolerance to be separated from them.

When we talk about two individuals who create a couple, we are talking about two personal and family realities. To achieve this, these differentiation processes are duplicated with the respective families of origin. It highlights the trajectory of each family, how they have lived and how they have faced the disability of their child. This could be uncomfortable, leading to competitive behaviour, rivalry and jealousy between the two families.

On the other hand, when a relationship functions and the families trust and support the common project of their children, these couples are consolidated as a family unit.

Internal functioning of the couple

The stable couples that we know give a lot of importance to the visibilisation rituals of their relationship: to get married, the banquet, the rings, are symbols of recognition for them that they yearn and rarely achieve, given the little social and legal recognition of their relationships.

In daily life they reproduce very different roles depending on gender. It is almost certainly the model that they have learned from their families of origin, which still prevails in our society, and gives them great security due to the clarity of the functions and the values.

In the eagerness to be consolidated as a family and to achieve some respect from their environment, they often relinquish their own individuality in order to function just as a couple. They stop doing things alone, they do not conceive individual decisions, or perceive them as a serious conflict. They occasionally use an alliance-couple to shield themselves from the environment, as it is always easier to blame someone else than face their own responsibilities.

Long-standing couples show us that all this progresses to greater man-woman equality and a greater flexibility in their internal organisation. The supports offered should be oriented towards these objectives.

Exploration of sexuality

The current sexual liberation of the society provides a lot of information and opportunities to explore sexuality, but a certain banalisation of the subject leads to the emergence of

myths that nurture a false collective image that often foments unrecognised insecurities and frustrations. Individuals with Down's syndrome participate in this context and its effects: they also want to build an image of normality of affective and sexual competence. In this situation, it is necessary to differentiate information from formation, to carefully analyse its importance, and adapt it to the expectations and needs of real individuals.

Some families request material that they offer to their children to give them information about sex. On one occasion a man with Down's syndrome asked his caregiver to rent pornographic films, but when he saw them he did not show any excitement, he had no better information and felt very uncomfortable. We cannot get round the fact that the aim of pornography is to excite but not to inform.

There is the idea that the sexual education of individual with Down's syndrome may lead to uncontrolled sexual practice, because they are incapable of handling their impulses. We need to eliminate stereotypes like these in order to discern the recourses that each person may require. If sexuality is denied, it results in a repression incompatible with their dignity, and to over-estimate their needs can similarly be negative.

We know couples with Down's syndrome who enjoy their sexuality, disregarding coitus. This evidence leads us to confirm the removing of the myths around genitalia and the richness of the possibilities to satisfy desire.

We have received requests for information on sex toys, sexual health, contraception and assisted reproduction, which were mainly based on curiosity and/or ignorance, and did not correspond to the real demand: "two women with Down's syndrome asked for information about artificial insemination, because they had decided that one would become pregnant and other would give the semen". We must attend to these demands without fear, with clarity and responding the specifically expressed doubts. On one occasion, a woman with Down's syndrome went to a pharmacy and asked for a "vibrator", and as a response the surprised pharmacist sold her a thermometer.

The new technologies that allow access to sexual contents and participate in virtual environments: enter chat-rooms, contact pages, exchange erotic images, etc, are practices they also usually take part in. It is important to support them and help them to protect their privacy and integrity in these situations.

Homosexuality

We do not have any specific literature on relationships between individuals of the same gender with Down's syndrome, but we should assume an incidence similar to the general population. We have known people who have played some type of sex game with someone of the same gender, with no great significance for them. They are exploring and discovering, but they are not considered homosexuals. We also know someone who clearly manifests as a homosexual, who has the support of his confidants and who complains of the difficulties of being able to have relations as a couple. We also know of other people who are defined as friends, who recognise what they want and enjoy being kissed,

caressed, or touched, but none of them are homosexuals. They may alternate these practices with other heterosexual relationships, while they stabilise a relationship based on an intense friendship with elements of clear intimacy.

From the normality, we must offer a climate of confidence in order to be able to accompany and respond to specific demands. We should never presume anything that is not confirmed by the individual him/herself.

Paternity/maternity

The desire to have children is inherent on being human. Individuals with Down's syndrome also have this desire. There are some references to women with Down's syndrome who have become mothers due to their relationship with a partner with another type of intellectual disability (see Azevedo Moreira's article in this same journal). We only have one or two references of men with Down's syndromes who have been fathers, for this reason, male infertility in this syndrome is mentioned.

Our experience with couples with Down's syndrome is that they themselves renounce having children. This decision is often the result of the information and sexual education process but, mainly, it takes place at a time when the individual recognises and is capable of thinking of the hypothetical child as an individual with his/her own needs. On some occasions, this desire is supplanted by other expectations, such as "to have a dog". Although we recognise these expectations as indicators of adulthood and normality, it is necessary to differentiate personal aims and establish the importance implied by each decision.

Legal aspects of couples with Down's syndrome

We have little experience of couples with Down's syndrome or with other types of disability, and even less on that they may be legally constituted in marriage. Some reports explain that they have achieved sufficient assent to be able to live together but not to be married. The negative is argued, referring to the complications that may occur and appeal to the prevailing sentiments. In some cases alternative ways are looked for to ritualize the union without any legal or civil significance: they have a party or exchange rings.

The need for support serves as a pretext to exercise control over the couple, taking away the freedom to make important decisions of their common project, but we should not forget that access to full citizenship leads to enjoying the civil rights. And these are an indicator of social inclusion.

Separations and breaking up of the couple

In our culture, we have normalised the separations of couples and that love is not for life. Even so, a separation is a painful and difficult to face process. Neither is it easy for individuals with a disability, and they require different types of support (legal, financial, logistic and emotional advice).

We continue to perceive a separation as a failure due to a conflict, and there may be denial of the problem mechanisms by the individual or by his/her environment. A certain capacity of self-determination is required to recognise the signs of unhappiness, in order to analyse the causes of the problem, to weigh up different solutions or to start negotiating some of them. Faced with this, the individual will need prudent, respectful help adapted to his/her real wishes and will.

On some occasions we have seen a first reaction of avoiding the environment due to the conflict, as if there had not been any error, change or failure. In these cases, an eagerness of overprotection in an attempt to avoid suffering comes into play. In others, we have found an excessive proactivity by the family to take control of the situation and resolve it without taking into account the responsibility of the individuals themselves. They are opposite expressions of the same overprotection.

Their reality again shows us the resilience of the individual with a disability, and that these experiences form part of a true life project that favours personal growth.

Conclusions

Once again, the reality demonstrates that the abilities of people with a disability depend as much on their own characteristics as on the environmental conditions in which they live. To live as a couple is a new reality which adds normality to their lives. What we consider exceptional today should be an opportunity shared for the majority in

the future. We will be prepared to help them make their life projects a reality. They have the right to do so.

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