Sexual Scripts for Individuals with Intellectual / Developmental Disabilities

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Abstract

This article examines the use of sexual scripts in the framework of sex therapy for people with intellectual and developmental disabilities (IDD).The project described here was instituted with young people integrated into Israel's special education system and later residing in hostels.

Keywords: sexuality, sexual scripts, intellectual and developmental disabilities.

Introduction

Human sexuality should engender feelings of completeness, vitality, and meaning; it can improve intimate relations, heal a sense of emotional loneliness and immunize us against communication messages that may harm our sexual self-image and make us feel unworthy of enjoyment and pleasure (Tapper, 2000). 'Great sex' has been described as: experiences full of vitality, a focus on the present moment, realization of a profound connection between two partners, intimacy that includes affection, acceptance, mutual respect and trust, verbal and non-verbal communication, partnership, empathy, and a spiritual experience of happiness and healing (Kleinplatz et al., 2009).

The recognition that people with disabilities are also sexual beings is relatively new and until the 1970s, there was little research on the subject. Despite the growing acknowledgment of developmentally and physically disabled people's rights to sexual expression, the process is still associated with fear, myths and uncertainty regarding their sexuality. In addition, the attitudes of family and care team members greatly influence the sexuality and quality of life of people with disabilities. As a result, they abstain from sexual experiences (Di Guilio, 2003).

As opposed to perceptions of sexual expression in young people without intellectual disabilities, attitudes towards intellectually disabled teenagers are significantly more conservative. Many intellectually disabled teenagers reside away from their family-of-origin homes and care teams have a much greater influence on their daily lives, at times leading to conflicts between parents and care givers. In some instances, parents have much more conservative attitudes towards their children's sexuality, possibly due to the fact that care teams are generally much younger than patients' parents (Cuskelly & Bryde, 2004).

The issue of whether people with intellectual disabilities are capable of make decisions about having sexual relations is at the center of discussions among researchers and professionals. The ability to give informed consent or to participate in sexual activities require an understanding of sexual behaviors, the willingness to engage in sexual relations, comprehending the possible consequences of sexual activities, understanding moral aspects, the ability to exercise freedom of choice, understanding the right to say 'no' and comprehending the possibilities of exploitation. Nonetheless there is widespread agreement that intellectually disabled people should be enabled and encouraged to make decisions for themselves whenever possible (Murphy & O'Callaghan, 2004).

Accepting the notion that disabled people are unable to have responsible sexual relations leads to this population developing negative beliefs about and attitudes towards themselves and potential partners. At times, these self-perceptions of their asexuality serve as a self-fulfilling prophecy and cause them to refrain from intimate and sexual relationships (Di Giulio, 2003; Milligan & Neufeldt, 2001).

Challenges

As detailed below, people with IDD generally require a great deal of mediation in their daily lives, and need full or partial support for complex activities. They manifest difficulties in language, abstract thought, planning, self-conduct, problem solving, social judgment, flexibility, and protection. All of these factors influence the way they are accepted as sexual human beings. From a physical standpoint, people with IDD sometimes require help with toileting, showering, dressing and undressing, maintaining personal hygiene, shaving, changing pads during or tampons menstruation and using contraception.

From cognitive, psychological, emotional and social perspectives, mediation and learning encounter challenges in almost every area, as well as in the sexual realm: : understanding the meaning of affection, what being a couple is and what intimacy entails. In the dating stages, questions arise such as how does one prepare for social encounters/dates, or

how does one behave on a date/social encounter. Additional issues include deciphering and understanding body language, comprehending the other's intentions and behaving accordingly, moderating reactions and learning restrain, enjoying oneself together and apart, reaching joint decision and how to guarantee the right not to agree. Finally how are sexual relations carried out, how does one choose and/or how to use contraception.

When personal independence is limited, privacy is also impaired, e.g. doors without locks, rooms without doors, sharing rooms (Weiss, 2015), sharing showers with other adult flat mates, parents who still shower their teenage children, care teams and /or parents who choose what teens should wear and sometimes even dress them. Additional potential problems include finding time and place for masturbation, getting permission to approach a partner and learning how to do so, as well as finding the time and place for a range of physical intimacies. In some situations counselors supervise couples during sexual activity, and require that clients seek permission for private time and permission to masturbate..

The influence of parents and care staff on intellectually disabled people's lives is enormous. Care staff's personal beliefs and attitudes affect the level of responsibility they are prepared to allow with regard to the sexuality of intellectually disabled young people, including the extent of their fear of client pregnancy, sexual harm or losing control. Research findings indicate that sexual relations between intellectually disabled people are rare ,possibly due to care givers' and parents' restrictive approach (Aloni, 1998; L'Ofgren-Martenson, 2004). 4

And despite their dependency on surrounding support s such as care teams and parents, when people are available to listen and offer support respectfully, chances are greater that young people will develop positive self-images despite their dependency (L'Ofgren-Martenson, 2004).

For people with IDD there may be added challenges. During genital sexual intercourse, partners have to deal with odors and fluids remaining on fingers, hands and clothes (Gagnion & Simon, 1973), flooding senses with smells, noises and textures to which they have not been accustomed, and impacting on high or low sensitivity thresholds. Clients may also exhibit difficulties with self-regulation and with their desire to instantly gratify sexual arousal; 'I must touch' versus 'I want to touch'.

Another treatment task is finding time and place for a couple's privacy in a hostel, which often requires systemic intervention: firstly, permission to be a couple, then staff who will allow a couple to miss structured group activities (Aloni, 1998), encouraging a couple's roommates to allow them privacy, and consent from relevant legal guardians for couple intimacy and/or sex therapy. In addition to minimal privacy in their place of residence, lack of sexual experience challenges care givers regarding sexual references, explanations and examples, necessitating caution when designing sexual scenarios.

One of the features of sex therapy is the range of infinite possibilities and creativity. This is true for all clients, and particularly for people with disabilities. . In such cases, the therapist must be creative in order to assist the couple toward intimate interaction. The clinical focus is on permission for sexual talk and feelings, on granting legitimacy for desire, and on expecting and removing barriers. At a later stage of therapy, intervention is required to restructure anticipation into something concrete using supportive visual aids. Since most people with IDD have broad learning disabilities, visual aids enable learning, comprehension and support prior to practical experience. In such cases, a sexual scenario becomes visual.

Using pictures to illustrate sexual issues helps therapeutic discourse and constitutes a way of overcoming verbal challenges.

Sexual Scripts

The origins of sexual scripts (Gagnon & Simon, 1973; Simon & Gagnon, 1984) are found in perceptions, beliefs, and social and cultural norms with regard to the manner in which we are meant to act in sexual or romantic encounters. A functional script reveals in detail the situation, the story, the roles of the actors, their behavior and future events that will occur. The script affects an individual's behavior on three levels: cultural script, interpersonal script and intrapsychic script. An individual's behavior during a sexual encounter expresses the sexual perception in a collective culture and private sexual perceptions and expectations. Combining these perceptions is what determines the meaning, setting and even emotions that participants will feel during an encounter.

Cultural, interpersonal and intrapsychic influences are different in every environment, with individuals' hidden wants and desiresconnected in meaning and social environment. In addition, biological and sociological development has a significant influence on meanings that sexuality or a lack thereof acquire in people's assessment of themselves and

others. Even cultural scenarios greatly affect the design of intrapersonal scripts and their origin, generally during adolescence and young adulthood.

Use of sexual scripts is often an effective tool in treating cases of sexual dysfunction. In such situations, a detailed evaluation is made of the revealed and/or imagined scripts of each partner from the point of complexity, rigidity, convention and satisfaction. The script will include routine sexual activity between partners and propose investigation, experiences and other possibilities to couples (Leiblum & Rosen, 2000).

In couples therapy, when there are different intimate expectations, a 'sex script' can assist in dealing with what takes place in the bedroom helping the couple reach a joint decision regarding how far they want to go. In addition, specifying the different steps along the way can reduce anxiety and neutralize the element of surprise, so that each individual will 6 be able to anticipate which behavior is acceptable to both partners. Assistance is provided on three levels- setting, structure and behavior specifically where, when, and what to do on each step, where to stop and/or how to check whether it is acceptable by both partners to continue

Sexual scripts as part of sex therapy for people with intellectual and developmental disabilities

While social stories have been utilized in sexual education for people with autism (Tarnai & Wolf, 2018), Augmentative Alternative Communication (AAC,) a large part of sex therapy for people with DDI, serves to clarify personal attitudes, encourag legitimization of sexual anticipation, and explor the possibilities available to clients living in their parents' homes and/or hostels. The role of the therapist is to enable clarification and expansion of patients' existing personal scripts and expectations. This is a process of joint creation including clarification of wishes, desires, prohibitions, fears and uncertainties.

The sexual script developed in Israel for IDD clients was created in the form of an illustrated book. The pictures serve as a guide to 'time together' with a partner. At times, the therapeutic process is prolonged and one of the significant tasks is finding 'time together' at a couple’s place of residence, during the week until the next session. 'Time together' enables legitimizing desires, joint investigating and exposing opportunities for sex and pleasure. As mentioned previously, 'time together' requires the intervention of a number of framework care figures - parents, management, counselors, roommates - in order to create a workable scenario.

The sexual script answers the questions: what will happen after leaving the therapy room. What will the couple do during their 'time together'? Using a visual sexual script enables an explanation of 'time together'. In general, the challenge of therapy is in turning words into deeds, turning anticipation into actions. When the potential for sexual partnership is on the agenda, with issues of legitimization always in the background, using pictures thatdescribe in detail the sexual script written by both partners, optimally results in a visual understanding of what is permitted and possible.

The series of pictures describes a visually clear sexual script, which is processed in and taken from the therapy room. The tangible script provides a sense of protection, reduces the fear of what is about to happen, allows intimacy in a scenario that is clear and known in advance to both parties. The book of illustrations can help limit physical and mental harm such as: uncertainty about physical positions that suit both partners, or the inability to find the right place for penetration.

We have found that it is preferable to use pictures of 'what is permissible' rather than 'what is forbidden/ or what do we not want to do' in order to prevent confusion and misunderstanding.. In addition, no text is required as pictures are enough to describe the behaviors. This helps particularly in cases where patients cannot read.

The wikihow.com website provided a collection of pleasant, clear pictures, which patients with IDD could easily understand. For example:

These sexual scripts serve therapists as well. Since the ability of DDI clients to remember and recreate events may be impaired, and the time that passes between one therapy session and the next is often a week, thus returning to pictures encourages conversation and enables therapists to understand what occurred in the room, how clients felt at every stage, when and if they chose to stop, and whether they want to investigate and experience other directions, such as adding pictures and/or changing the existing script. Encouraging flexible thought is enabled by playing a game with the pictures, introducing changes and thus opening sexual investigation.

The ability to encourage flexibility, spontaneity and expanding the sexual script depends on the extent of patients' disabilities.

Since it is difficult to obtain permission and/or informed consent from clients with IDD or from their guardians for the use of case material, what follows is an example of a sexual script characteristic of the above population. Each stage requires a detailed explanation of concepts that are sometimes unknown such as: date, reciprocity, small talk, French kiss and/or body parts such as mouth, lips, tongue, and ear lobe. In addition, learning focuses on how to decipher a partner's consent or unwillingness and to act accordingly, and sometimes simulations of what will take place in a room such as: inviting on a date or encaging in conversation.

The partner who takes the initiative for an intimate encounter will approach a partner and verify whether the wish is mutual.

The encounter can begin with sitting together,
physical closeness, talking about how the day has been. It can then move on to the following stages:

Hug closely

Kiss on the cheek

Kiss on the mouth

Lying on the bed with clothes

Experience mutual discovery and pleasure

Eye contact in bed

Sometimes one stage of intimate contact also requires additional visual details for example: French kiss

We have used this technique with 15 couples and individuals. Example of effectiveness included:

□ □ A young woman 25 years of age diagnosed with Down syndrome andintellectual disabilities who was able to change sexual behaviors with her partner and confidently say no to his requests.

□ □ A couple diagnosed with intellectual disabilities was helped to understand the option of sexual contact without any clothing.

□ □ A 40 year old man diagnosed with intellectual disabilities was helped to understand the sequence of activities to enable him to begin a physical relationship.

□ □ A 14 year old boy diagnosed as severely autistic was helped to learn about his masturbation, resulting in a reduction in his inappropriately touching others and finding private space for this sexual activity.

In creating a book of sexual scripts it is helpful to include pictures that have personal significance for the client. This is particularly important when verbal capacity may be insufficient to achieve adequate understanding. Examples of this can be pictures of the client's bedroom or bathroom and to emphasize the behavior appropriate for those locations, such as masturbation or sexual contact with a partner.

Limitations

Despite clarification of partners' desires and expectations and building together the sexual script, the use of a concrete-visual tool can limit the possibilities and harm the authentic, sexual interaction woven during intimate moments. We have also questioned the extent to which the sexual script is open to or restricts possibilities of expansion?

Also, do patients have much ability to make decisions different from those taken in the therapy room, and to act differently, while deciphering signs of enjoyment and consent from the other party (Murphy & O'Callaghan, 2004)?

Sexual scripts, as described in the article will not be appropriate for blind clients, in which case other creative ways will be required to build a mutually acceptable sexual script.

Conclusion

Systemic work with parents, care teams and patients themselves is essential to raise the quality of life for people with IDD. In this article we have emphasized the importance of the right to sexual pleasure for this population and presented a new option for sex education and therapy. This entails training educators counselors and therapists in the use of Augmentative and Alternative Communication (AAC) to promote sexuality. The goal is to approach the subject of sexuality without fear when it arises in the therapy room and to overcome the limitations of spoken language.

Our responsibility is to relate to the sexual development and sexual desires of this client population and to provide them with the guidance necessary for a safe and satisfying sex life.

Those wishing for further information about this technique are invited to contact Sigal Vintor: sigal.vintor@gmail.com

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