

Sexual health in young people with connective tissue disorders

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Abstract

Development and exploration of a sexual identity is a normal and integral part of adolescence. Long term conditions such as connective tissue disorders can potentially impact this development. Health professionals involved in the care of such young people need to be aware of their sexual health needs and have the necessary skills and knowledge to routinely address these in clinical settings. This paper will explore aspects of sexual health specific to connective tissue disorders in addition to those which are generic to any young person seen in any healthcare setting.

Keywords adolescence; connective tissue disease; juvenile SLE; sexual health; sexuality; youth friendly health services

Introduction

Adolescence is a developmental stage (10–19 years of age) where experimentation in all parts of life is common as the young person evolves their own identity. Development and exploration of a sexual identity is a normal part of adolescence. The adolescent may however be lacking in knowledge of sexual health and relationships, leaving them vulnerable to problems relating to sexual activity.

The connective tissue disorders (CTD) are a heterogeneous group of autoimmune inflammatory conditions with multisystem involvement, including SLE and systemic sclerosis. This paper highlights the important aspects of adolescent sexual health of which a healthcare professional should be aware. Aspects specific to CTD will be presented in addition to those which are generic to any young person seen in any healthcare setting.

Epidemiology – why does it matter?

Sexual health in adolescents in the UK is poor when compared with their European counterparts. In the UK there is a higher rate

of teenage pregnancy and of sexually transmitted infections (STIs). STIs are more common in young people aged 16–24 than in any other age group. There is now a plethora of sexual health advice available to young people, yet it can often be confusing and difficult to access the right information and/or services. In a large UK school-based national survey, half of year 10 students did not know of a local sexual advice clinic. Adolescents will approach a variety of people for advice including their peers, parents and health professionals, as well as a range of media. It is therefore important that all health professionals who come into contact with adolescents are able to give appropriate advice and signpost to sexual health services where necessary. This is undoubtedly true of those who care for adolescents with CTDs. Since they require regular medical follow up, the health professional has an opportunity to develop a relationship with the adolescent and therefore engage in discussion about sexual health issues, including those which are specific to CTDs.

Talking about sexual health

An understanding of the legal framework underpinning this practice is fundamental to any discussion about sexual health. In the UK, the legal age of consent for sexual intercourse is 16 years. As previously discussed, sexual activity is increasingly prevalent in adolescents below the age of 16 years. The scenario of an “underage” individual seeking medical advice regarding sexual health issues is therefore common, and refusing to give advice and treatment without parental consent would breach a range of ethical principles which underpin our practice. In England, the law will support a practitioner offering sexual health advice if certain criteria, namely the Fraser Guidelines, are met (Table 1).

The law assumes that adults over the age of 18 are competent to consent, and it is the practitioner's responsibility to identify and raise concerns if they believe this may not be true. In young people under 16 the reverse is true, and it is up to the practitioner to prove that they are satisfied that the adolescent is sufficiently competent to consent. The age of competence will vary between

Fraser guidelines for giving contraceptive and sexual health advice and information to under 16 year olds without parental consent

Are you satisfied that:

- The young person can understand the advice and has sufficient maturity to understand what is involved in terms of the moral, social and emotional implications (Gillick Competence)
- You can't persuade the young person to inform their parents, nor allow you to inform their parents that contraceptive advice is being sought
- The young person would be very likely to begin or to continue having sexual intercourse with or without contraceptive treatment
- Without contraceptive treatment the young person's physical or mental health or both would be likely to suffer
- The young person's best interests requires the professional to give advice without parental consent

Table 1

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individuals, and depend on the complexity of the treatment. Between 16 and 18 years, the law generally allows adolescents to consent for a procedure to take place, but legally they cannot refuse.

It is vital that the adolescent feels safe in the environment in which sensitive issues are discussed. A clinic should provide an adolescent-friendly environment from the outset. This includes the manner in which they are greeted by the receptionist, the environment of the waiting room and the manner in which they are treated by the outpatient nurse. This will influence their perception of the clinic and thus of the clinician who sees them. Appropriate furniture, leaflets and posters (including those assuring confidentiality) in the waiting area add to the ethos of the clinic.

Seeing adolescents independently for at least part of the consultation is a quality criteria of a youth friendly health service. This is an important developmental step in the process of transition to independent healthcare. It also gives the opportunity to discuss more sensitive issues. An adolescent may decline to be seen without a parent present. It is important to recognize that this is a valid decision, but it is often worthwhile gently exploring the reasons behind this.

Confidentiality has been found to be of prime importance to adolescents in healthcare settings. An adolescent (particularly one with unsatisfactory relationships with their parents, those who exhibit health risk behaviours and/or have mental health issues) is unlikely to disclose personal information if they believe the clinician will immediately divulge the information to the parent/guardian. In order to benefit from independent access to clinicians it is important to ensure at the outset that this principle is understood by both young person and parent. It should also be made clear that there are certain scenarios where it is necessary to breach confidentiality. The latter are when information is disclosed that puts either the individual or another person at risk of "serious harm". It is useful to give examples of what is meant by "serious harm" to ensure understanding.

The HEADSSS interview (Table 2) is an aide memoire for routine psychosocial health screening. Screening provides an opportunity to engage young people, assess their progress through adolescence, identify strengths and areas of concern and assist in the design of treatment interventions. It is well recognized that risky sexual behaviours are associated with other high risk behaviours such as smoking, alcohol and illicit drug use. Screening adolescents for these other behaviours may help identify those with sexual health needs.

HEADSSS Psychosocial Screening Tool

Home
Education
Activities
Drugs + Alcohol
Sleep
Sexual health
Suicide and emotional well-being
Safety

Table 2

Some clinicians may find starting a conversation about sexual health difficult. Despite possible initial embarrassment, many adolescents welcome the opportunity to discuss such issues as part of holistic healthcare. It is important to give some warning that you are about to ask sensitive questions along with explanations that this is routine with young people of their age. Initially diverting the conversation from the individual themselves, but asking about their friends can be a useful way to deflect some initial embarrassment (see Table 3).

When talking about sexual health it is important not to make any assumptions, including sexual orientation and always use gender-neutral language. In a UK school-based study 3–4% of 10–15 year olds reported worrying "quite a lot/a lot" about whether they were gay or bisexual. Having had a same-sex sexual experience does not mean a young person is homosexual/bisexual. For those who do identify themselves as homosexual/bisexual, and for those who are uncertain, this can be a particularly confusing time. There may be added pressure of stigmatization, or perceived stigmatization of homosexuality in families, peers and the wider society. It is not the role of the healthcare professional to determine an individual's sexuality. It is however important to recognize that this may be an issue for some young people in healthcare settings, and to be sensitive and supportive in the difficulties that they face.

While many adolescents are open and honest with clinicians, others find it more difficult to engage in conversation. This is a challenging scenario, when even the most open-ended enquiries can result in single word answers. A change of tactic is often required and there are a number of alternate approaches. (Table 3). When talking about sex it is important to ensure a mutual understanding of the terms being used. "Sex" and "sexual activity" do not necessarily refer to vaginal intercourse. To adolescents, the terms may refer to anal penetration, oral sexual acts or even kissing.

Some useful trigger questions

(i) Examples of introductory questions

"Some young people of your age are in a relationship with someone? Are you?"

"Do you ever talk with your friends about sex? Have any of your friends had sex?"

"Some young people of your age have had sex, have you ever thought about having sex?"

(ii) When the young person responds with : "I dunno"

Rephrase the question:

What do you think your friend/parent/sibling would ask/tell me if he/she were here?

Some young people your age ask me about [xxx] have you ever wondered about this too?

Would you like to hear what I tell other young people about [xxx]?

(iii) Clarification of understanding of terminology used to ensure they understand you and you understand them!

"may I just check with you what you mean/understand by [xxx]?"

Table 3

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