

Sex, body image and relationships: a BRIGHTLIGHT workshop on information and support needs of adolescents and young adults

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Abstract:

Purpose: Discovering sexuality and romantic relationships are important development milestones in adolescence and young adulthood. A cancer diagnosis imposes obstacles for young people such as changes in their sexual function due to the disease and/or side-effects of treatment, body image concerns, and interpersonal relationship difficulties. This can cause psychological distress and can impact on quality of life. We aimed to explore sexual health information and support needs of adolescents and young adults with cancer.

Methods: Five young people aged 16-24 years, with a previous cancer diagnosis when aged 13-22 years attended an in-depth four-hour workshop. The framework approach was used to analyse workshop transcripts.

Results: Three overarching themes emerged: (i) information sharing; (ii) contexts and relationships (influencing factors); (iii) information sharing preferences. Information shared by healthcare professionals was focused on a medicalized view of sex with symptoms, infection control and protected sex at its core. Young people had unanswered questions related to sexual function, the impact of cancer and how to manage it, and about pleasure, body image and relationships. Parents presence at clinical consultations inhibited discussions about sex. Young people wanted professionals who were comfortable to talk about sex with them.

Conclusion: Young people exhibited significant unmet needs around information provision on sex, body image and relationships. They wanted information to be given by professionals and access to online resources. Development of training for professionals and resources to support young people requires further work.

Introduction

Our sexuality is a fundamental aspect of who we are as human beings and sexual development are important milestones of adolescence and young adulthood (AYA). The period of adolescence begins around 13 years and the upper range of young adulthood varies been 24-39 years depending on jurisdiction.¹ During this period, the influences of biologic sex, gender identity, sexual attraction and orientation are consolidated into behaviours and expressed in the context of relationships through a complex developmental process.² A diagnosis of cancer at this time compounds the complexities of achieving sexual developmental milestones.³

Cancer has negative physical and emotional impacts on sexuality and sexual function. Treatment and disease related side-effects include vaginal dryness, pain, decreased libido and inability to achieve orgasm super-imposed on broader treatment effects which impact on body image and self-esteem.⁴ Side-effects differ between cancers and treatment regimens; however, a commonality among cancer patients is the profound impact on body image and consequential negative influences on romantic relationships and intimacy.³

Sexual health issues are widely reported by childhood cancer survivors⁵ and older adults⁶ but less is known about those diagnosed during adolescence and young adulthood. Currently, fertility issues dominate the AYA research agenda, an important issue, but encompassing only one part of sexual health. Young people's unique healthcare needs are increasingly recognised, and it could easily be surmised that issues related to sexuality are also unique due to the monumental physical and psychological changes occurring during this period. This includes but is not limited to sexual identity, exploration and learning from peers. Despite recognition of their unique needs, evidence describing the impact of cancer on young people's sexual health is limited.²

We previously identified that young people wanted young person-related information as well as cancer information. Young people gave the example of information on sexuality being removed from a specialist AYA unit (for patients 16-24 years old) as parents found it 'distasteful'.⁷ Sexual function, sexuality and intimacy are shown to be important supportive care needs for young people with cancer. However, information in this area is either unavailable or insufficient to their needs.⁸

The BRIGHTLIGHT Young Advisory Panel (YAP) is a patient user group experienced in advising with study concept, design and management. The YAP requested a workshop on sexual health and information needs, highlighting this as an area of unmet need. We sought to explore the sexual health information/support needs of AYA during and after cancer diagnosis as an initial process of patient-led research.

We aimed to understand:

1. What information/support on sex, body image and relationships were being offered to young people during cancer diagnosis and follow-up?
2. Did the information/support provided about the impact on sex, body image and relationships meet the needs of young people?
3. What was the impact of the current information/support they receive?

Ethics

The project was approved as part of the BRIGHTLIGHT patient and public involvement strategy by London-Bloomsbury Research Ethics Committee (11/LO/1718). Prior to attending, participants received information about the day and gave written consent following. Following the workshop, participants were contacted by a team member to ensure the workshop had not elicited any distress.

Participants and setting

Five young people (two male) who were established members of the YAP attended a workshop conducted in a non-clinical setting. Young people were 16-24 years at the time of the workshop and had been diagnosed with haematological cancer (n=3) and solid tumours (n=2) when aged between 13-22 years. The Group comprised of gay and straight participants. To protect the anonymity of the YAP no further demographic details are included.

The workshop also included three researchers known to the participants and a facilitator (BL) who was an expert in using creative methods to discuss cancer, sex and relationships. The facilitator also had experienced a cancer diagnosis as a young adult. The researchers participated in activities 1 and 2.

Methods

Activity 1: Unanswered questions about sex and cancer

Young people were asked to write on a postcard two unanswered questions they had about any aspect of sex. This allowed young people to reflect on questions they had around sex, body image and relationships.

Activity 2: Creating a space of intimacy and confidentiality

The facilitator explained activity 2 would not be shared. Young people were given an A3 sheet of paper. Working individually, participants were asked to draw a full-length representation of their body. They were asked to mark an 'X' on a part of the body they found uninteresting, scarred, or they felt embarrassed about. Young people were instructed to count up the number of 'X's, fold the paper and write the number of X's on the outside of the folded paper. The Group reconvened in a circle and, in silence, were asked to pass the image of their body to the person next to them, to hold it and reflect on what it felt like to have someone else hold a representation

of their body and for them to hold another person's body. The three BRIGHTLIGHT researchers participated in this activity therefore exposing some vulnerability to the Group to foster sharing.

Activity 3: What advice you would give yourself upon diagnosis about sex?

Young people were asked to reflect individually on the time when they were first diagnosed and to think of what advice they would now give themselves about sex. They then worked in Groups of two/three to identify five key pieces of advice to discuss within the Group.

Activity 4: Focus Group

The facilitator led the focus group, which opened with a question to elicit young people's views on key pieces of advice to give a young person when first diagnosed *'What was the advice that you'd give yourself?'* Discussion within the Group was encouraged with the facilitator being reflexive with additional questions and some sharing of personal experience. There were prompts in the discussion guide to ensure all points were covered.

Activity 5: What are the big questions we need answers to about sex and intimacy?

Following the focus group, as final concluding thoughts young people were again asked to reflect on their questions around sex and relationships, and if those were different or the same. The facilitator asked the group to write down individually *'What are the questions, what are the big questions we need answers to about sex and intimacy?'*

Analysis

Activities 3-5 were audio recorded and transcribed verbatim. The transcript was analysed using Framework analysis, which included five stages: familiarisation of the data; identifying a thematic framework; indexing; charting; mapping and interpretation.⁹ Analysis was undertaken by one researcher (AM) and validated by two researchers (RMT; LAF).

Results

The unanswered questions submitted in Activity 1 were broadly themed around body image, fertility and sex during/after treatment (Box 1). For activity 2, participants were assured of confidentiality so it was not recorded. This activity was designed to create a space of confidentiality and intimacy and young people commented that they did appreciate the vulnerability of holding someone else's body and have someone else hold theirs'. The key pieces of advice young people would give themselves at diagnosis have been extracted directly from the transcript as stand-alone quotes (Box 2).

The analysis revealed three overarching themes: (i) information sharing (what, when, how, who); (ii) contexts and relationships (influencing factors); (iii) information sharing preferences (what, when, how, who) (Figure 1).

Information Sharing

Overall young people reported a lack of discussions about sex with healthcare professionals. Young people had questions about sex, but some felt embarrassed to ask, which left them with unanswered questions. This negatively impacted on romantic/sexual relationships:

"I either was too embarrassed to ask for these answers or didn't know where to find them independently. So I just kept my mouth shut until some points where it affected deeper than just sex. It was just, you know, disrupting relationships or making me frustrated"

Young people shared occasions where sex was discussed and in some instances described taking the lead: *"I emailed my doctor...asking whether, you know, is it okay for me to have sex? What should I do? What are the things to look out for? What I can and cannot do"*. Other

examples of conversations about sex, the 'how', 'who', 'what' and 'where' are described in detail in the next sections.

The medicalized view of sex – sex as risk

Young people reported the information exchange around sex was predominately medicalized and often rushed. Common characteristics of the process of information sharing about sex included:

- a) Focus on safe sex
- b) In a context where not enough time/space was permitted
- c) Close to diagnosis (when young people may not have had time to think about it).

The quote below shows also assumptions of sexual orientation and sharing of irrelevant/unhelpful information.

“Shortly after my diagnosis, I was pulled aside...[Clinical Nurse Specialist] just said, really, really quickly...‘If you do ever have sex during your treatment, make sure you use a condom because you can pass chemotherapy drugs from your semen into vaginal fluids...which isn’t very useful to me as I like guys”.

The medicalized view of sex focused on the use of protection, avoiding pregnancy, infection control, fertility and symptoms was a common theme and included a view of sex as something that could endanger the young person and/or partner.

“There’s infection control. I was told when you’ve got a low immune system that other people’s bits may be dirty. My bits may be dirty. So by having sexual contact with someone you’re at high risk of getting ill (...) it would be your fault if you were selfish enough to want to have sex and got ill. That other people would have to look after you”.

This quote also shows the balance/struggle between the autonomy (with the development of sexual relationships) and dependence on others if succumbing to infection/illness.

The idea of '*spreading*' chemotherapy to a partner was shared with them by healthcare professionals. Young people understood the key message being shared 'have protected sex', however, discussions about the actual impact of treatment or the risks of infection were incomplete and young people expressed some unanswered questions:

"If you're having all this information saying, it may or may not affect your fertility, how does that affect the need to have safe sex?"

Some symptoms and side-effects were mentioned and supported by written information; however, young people did not have the time/space to discuss how they could manage these in their relationships or strategies that could be used, leaving practical questions unaddressed.

"One of them [symptoms] is low libido. You bear the symptom of not wanting to have sex. Yes, that's pretty much it in terms of the conversation on sex, but as to what you can, you cannot do, what you should be doing, what you should be looking for. Then I have to ask".

Given the unanswered questions described previously, young people reported using the internet as a strategy to source information. However, this proved not to be reassuring and young people described further confusion, uncertainty and lack of trustworthy resources available, the latter impacting on wellbeing.

"I'd look things up on the Internet...All it does is it doesn't answer the question you have with a verified answer. You don't know if this is good advice...You get a bit anxious".

Contexts and relationships

Discussions about sex were influenced by context and relationships, including being in a paediatric or specialist TYA unit; time pressures on consultations; being on/off treatment; feeling

embarrassed/less confident and preference for healthcare professionals to address the issue first; parents being with them in the consultations.

The place of care influenced how the topic was addressed, with young people describing the topic not being addressed in paediatric settings: *“I don’t think I really had as much as I needed. I was, sort of, treated at a children’s hospital. Although they do up to sort of late teenage up to, sort of, eighteen and nineteen. They just don’t have the same understanding.”*

Time pressures and competing priorities within consultations resulted in a perceived lack of time for discussions around sex and intimacy. Additionally, the timing of when young people wanted to discuss their concerns varied depending on treatment status and what they were coping with. For example, when dealing with the information about diagnosis, and treatment they might not be thinking about their questions about sex. Nevertheless, young people wanted the information to be offered and to be informed where they could access this information at a later point.

Young people felt embarrassed or lacked confidence to bring up questions related to sex and intimacy unprompted; a lack of understanding of who was available to discuss this with them also existed (i.e., no named professional). They also reported healthcare professionals being uncomfortable to discuss sex and intimacy-related information with them and acknowledged that healthcare professionals might not be prepared to have discussions about sex, expecting some of these discussions to be school-based. However, young people may miss out on these lessons due to the timing of their diagnosis.

Importantly, young people may also miss out on discussions with their peers about romantic and sexual relationships. Peers are an important source of support and information during adolescent and young adulthood, but cancer can isolate young people from their peers.

“...not with normal friends because they don’t understand. It’s a different kind of conversation than you would normally have if you’re talking about sex with them”

The parental role was pivotal and discussed at length by the YAP. The conundrum was how to balance parental dependence throughout their journey and striving for autonomy. Young people wanted parents present in consultations and supporting them with information around diagnosis and treatment but might not necessarily feel comfortable talking about sex with the healthcare professionals with parents present.

Balancing the need for privacy and the parental role in all other aspects of care is important and extends beyond sex and intimacy conversations. Young people acknowledged that managing the parents’ role/presence in the consultations should be done in a way such that parents do not feel left out and suggested:

“Knowing my mum...If we’re together in a consulting room and then she leaves, it would be awkward when you leave the room...Maybe you go in on your own and then the person gets invited in, it almost feels like they’re being welcomed in rather than pushed out”

Preferences - What, How, Who, When

Young people reflected on what would support them to discuss their concerns and questions about sex and intimacy, and offered suggestions.

Who delivers information

Young people considered it acceptable for information to be shared by a nurse, doctor or other members of the multi-disciplinary team, as long as they were comfortable with the topic; this would also make them more relaxed and comfortable. They also needed to be informed about who they could talk to or available resources.

When is information delivered

Young people wanted ongoing access to information, even when treatment ends. Ongoing access is important because the information may be offered at a time when they are not ready or willing to discuss sexual relationships.

"...looking back on it now you think, 'I could have done with that conversation not for that moment in time, but for now, and I don't know where I'm supposed to go now to get that conversation'. So it's more about having it available"

What information is shared: Sex as intimacy

Sexual desire was influenced by treatment side-effects, these include: being *"Bald and fat"*; *"Scars and lines hanging out of everywhere"*; *"Spots"*; *"mouth sores"*; *"diarrhoea"*. These side-effects influenced young people's body image and had an impact on their sexual desire, but a lack of sexual desire was not an issue whilst coping with the other aspects of treatment and cancer. It was however, an issue when they were being more sociable or in a relationship. *"[chemotherapy] makes you tired, you don't really care...So if you're not satisfied with how you look at that time, you're not going to be comfortable doing those kind of things"*.

The way young people felt about their bodies, energy levels and sexual desire had an impact on the development of sexual relationships and intimacy. Accordingly, it was important for young people to discuss how to cope with the impact of treatment and managing sexual encounters to optimise the experience for both partners considering fatigue and other side-effects.

"Maybe there could be some kind of tool of 'Easy ways for sexual stimulation' kind of thing...If you haven't got the strength to do this kind of thing. Maybe-, because there are of plenty of tools out there that people use to do these things on themselves or on their partners"

How information is the shared

Young people's preferences varied: face-to-face contact with someone who was comfortable talking about sex and intimacy versus contact with someone they didn't know. However, others preferred email or live online chat favouring the anonymity which could facilitate the disclosure of intimate concerns and questions. Additionally, suggestions of how to include discussions on sexual needs in consultations were offered *"being told in advance they are going to talk about it in the next consultation. So they can prepare questions"*.

Finally, young people wanted *"the opportunity to talk about sex and intimacy now, later on and in the future, during or after treatment with someone that actually wants to talk about it"*.

When asked to reflect on their discussions at the end of the focus group the YAP were asked what the big questions were about sex and intimacy that needed answers. These are listed in Box 3 and illustrate that questions on the physical aspects of sex and safe sex persist despite these being described as topics covered by healthcare professionals. The unanswered questions also highlight the relevance of both physical and intimacy aspects of their informational needs about sex, body image and relationships.

Discussion

We aimed to explore what information on sex, body image and relationships young people with a cancer diagnosis were receiving, if this information/support met their needs and the impact of the current information/support. We found a deficit in information and support for these topics. Critically, information that was offered was highly medicalised, focusing on infection control and 'safe sex', and was often confusing as young people still expressed gaps in knowledge.

The impact of side-effects of treatment on young people's body image and sexual desire were consistent with existing evidence,¹⁰ which concluded that alterations in sexual function and

expression occurred in most young people during treatment and continues into survivorship.¹¹

Despite sexuality and body image being an integral to young people's psychosocial health and identity formation, the impact of disease and treatment on self-image and sexuality for this group has largely been overlooked.¹² The emphasis of care is often on cure and alleviation of symptoms, with sexual functioning being neglected.¹³

Our study showed the challenges in information sharing about sex and the related impact of the cancer diagnosis and treatment. Although healthcare professionals focused on a medicalized view of sex, this information was insufficient to cover the impact of chemotherapy on orgasm or risks associated with anal sex. Young people lacked information about what they could and could not do and why. Research has shown patients want to be informed about the impact of a cancer diagnosis and treatment on their sexuality¹⁴; however, healthcare professionals demonstrate reluctance in discussing patients' sexual practices and can be inconsistent in information provision.¹⁵ Personal and professional factors influence healthcare professionals' discussions around sex with young people. Lack of knowledge, education and training are the most frequently cited reasons.¹⁶

Competing pressures of other issues in time-restricted consultations in the presence of parents was an issue. Young people wanted their parents present at the consultation but also struggled to have them there when wanting to discuss sex and other emotional needs. They may not fully disclose this with parents present hence the need of ensuring sensitive discussions about sexual health take place away from parents, unless the young person requests their presence.

Confidentiality around these conversations must be assured and in keeping with other studies that demonstrate confidentiality is of paramount importance specifically for young people, lack of confidentiality may negatively impact on utilisation of services, and disclosure of risk behaviours.¹⁷

Research into the development of educational interventions is needed. As stated by Robertson et al.¹⁸ 'Addressing potential sexual difficulties would allow for preventative measures and provide AYAs with the knowledge and understanding of potential experiences post-treatment. Appropriate support and information may potentially reduce distress due to any difficulties experienced'.

The main limitation of this study is the inclusion of a small sample of self-selected young people who are co-researchers/collaborators in AYA research, so may present a different perspective to all young people. However, they represented a range of ages, diagnoses, gender and sexual orientation (this question was not asked but emerged during discussions) and place of care experience. Importantly, the YAP had worked with the BRIGHTLIGHT team extensively on research so had developed group bonds and were less inhibited in their discussions. This was further facilitated by the activity 2, which fostered confidentiality and trust through the experience of holding someone else's body.

Implications for practice

Implications for practice are two-fold. In order to facilitate discussions, it is necessary to develop training and support for professionals to feel comfortable in talking about sex and understanding young people's information needs. This could be implemented alongside online support tailored to young people. Information through the internet is acceptable to young people¹⁹ but the way such a sensitive subject is conveyed needs improvement?

Parent's presence at consultations can inhibit discussions about sex and relationship concerns. As a potential solution young people suggested having exclusive time with their healthcare professional at the beginning of the consultation prior to inviting the parent in to discuss other aspects of care.

Our study has shown young people still have questions about contraception, the impact of treatment on their bodies, sexual desire and relationships even when treatment has finished. They want information on the impact of the treatment and how to manage this; how to still maintain a sex life that is safe for both partners and is pleasurable. Clear and accurate messages are required around chemotherapy transfer, infection control and sexual activities – vaginal, oral and anal sex. Additionally, information is required around the lack of sexual desire, the impact of negative body image on relationships and how young people can negotiate these challenges and develop healthy romantic and sexual relationships.

Our findings showed that young people had unmet needs of information provision about sex, body image and relationships. We reported their preferences, providing evidence to support further work in this area. Young people wanted professionals who were comfortable talking about sex and to approach about it. They wanted ongoing access to trustworthy resources, time in consultations to facilitate these discussions without being accompanied by their parents. Given the importance of developing sexuality during adolescent and young adult years, it is crucial to understand the factors that enable their information/support needs to be met to attain these milestones and maintain healthy sexual relationships during and after treatment. Interventions are needed to support young people and professionals.

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Box 1: Unanswered questions about sex and cancer

Can you have kids after receiving chemo?

Can you have sex whilst receiving treatment?

Does Chemotherapy affect my partner through sexual intercourse?

Does your fertility get affected?

How soon after chemo can I have sex?

When can I start having sex again?

Why would anyone find me sexually attractive right now?

Will it affect fertility?

Will my chemo affect my ability to orgasm?

Will treatment reduce intensity of orgasm?

Would there be any risks involved in having anal sex, compared to anything else?

Box 2: Key pieces of advice for young people newly diagnosed with cancer

Being confident to ask the question at the time, don't be nervous

The question of need to know about it now. You need to know about it in the future

Get the information about how relationships going to be affected at that point. So then you can factor that in and try counteract that

Don't go around trying to please everyone else. Don't make it such an important part of your experience

Don't try and get into a relationship too soon... just avoid that stress

Box 3: Young people’s responses to ‘What are the big questions we need answers to about sex and intimacy’

“Will I ever be able to feel sexy again?”

“Does treatment physically affect sex organs, like penis size and such?”

“Can female sex drive or arousal be improved with hormone therapy?”

“Is it safe to use the pill or oral after high-dose chemo?”

“Is it okay for me to have sex during chemo?”

Figure 1. Sex workshop framework

