The Sexual Health Information needs of TYA’s with Cancer

Beth McCann
Clinical Nurse Specialist for Young People with Cancer
Discuss whether TYA’s with Cancer have specific SH Needs

If so – why? What is different from the general TYA population

What are the barriers in addressing their SH needs?

What information should we be giving YP?

Implementations for future practice
TYA’s with Cancer have unique physical, emotional and psychosocial needs
(Nice 2005, AYA Oncology Progress Review Group, 2006 & Zebrack 2011)

One particular element of TYA cancer care that encompasses physical, emotional and psychosocial care is sexual health

Limited body of existing research
Sexual development is a central theme of adolescence (Krebs 2012)

Sex is paradoxically the forbidden fruit and the holy grail in adolescence (Sutton et al 2001)

Few other combinations of 3 letters are so cloaked in mystery and fraught with emotional, developmental and health implications.
Do TYA’s with Cancer have different sexual health information needs?
Specific themes relating to sexuality issues in TYA’s with Cancer

- Gaining sexual health knowledge

YP need accurate and comprehensive information about sexuality to practice healthy sexual behaviour.

Literature suggests that the most reliable source of information is that which they obtain through their formal education.

Interrupted education.

Propelled into a level of knowledge that they are unprepared for.

Peer discussion

Protective parents
Sources of Sexual Health Information

Parents  Peers

TV  Internet

Healthcare  SEX  School

Magazines  Music

Films
Media Influence

- Sexual Health content is frequently portrayed in the media either ambiguously, inaccurately and generally in a way that negates inclusion of responsible and safe sex messages.

- 2/3 of 13-17 year olds said they had viewed pornography.

- 60% of teenagers said that pornography had an impact on their sex lives and affects their self esteem and body image.

(Young People and Pornography A briefing for workers (2009) Brook, Centre for HIV & Sexual Health, FPA, National Youth Agency)
Influence of pornography

Video cannot be provided
Specific themes relating to the impact Cancer can have on the SH of YP

- **Gaining sexual health knowledge**
  (Interrupted education, Peer discussion, protective parents)

- **Difficulties in Interpersonal relationships**
  (developing romantic relationships, isolation from peers-meet & evolve. Pity – viewed as a ‘sick’ person. Surrender independence, physical effects of tx. Disclosure of Ca dx)

- **Body Image Concerns**
  (side effects of medications – hair loss, weight gain, acne, stretch marks, scarring, amputation, asymmetry. BI can be of greater concern than their own mortality. Different from peers-exacerbating feelings of abnormality and unattractiveness)

- **Identity**
  (Forming sexual identity & reproductive capacity are key developmental tasks in TYA. Impact of Cancer on fertility and psychosexual identity can be potentially devastating. As YP develop their identity, they may also be exploring their sexual preferences and gender attraction. Peer relationships are integral to adolescent identity)

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Recent studies have identified that people of all ages want to be informed about the impact that a cancer diagnosis will have on their sexuality.

However, research indicates that HCP’s are reluctant to raise the topic and are inconsistent in providing information and education in this area.

A common theme overwhelmingly evident in the literature is that HCP’s are consistently failing to address the sexual health and sexuality needs of their patients.

Culture is saturated with graphic images but there is a lack of frank conversation about real sex.
- Lack of knowledge, information and training
- Lack of sexuality education for HCP’s in their training
- Lack of knowledge around specific dysfunctions associated with particular diseases or treatments and possible interventions
- Emphasis of care is often focussed on cure and alleviation of symptoms, resulting in sexual health being neglected
- Some HCP’s may not be comfortable with their own sexuality or feel that discussing it is an invasion of patients privacy
- Confusion about who is responsible for initiating conversation
- HCP’s may feel that if the patient wants to know – they will ask
- YP say that they trust their medical team to raise important issues – if HCP’s don’t raise it does that mean it isn’t important?
‘The Chat’
‘THE CHAT’

Right ....... who's going to have 'the chat' with him?

OMG - I can't do it ... what would I say ??

Yikes I'm outta here!
What do we need to discuss with YP?

- Establish where the discussion will take place and who will be present (PRIVACY!)
- Collaboration with parents
- CONFIDENTIALITY
- Do not say .......It’s embarrassing!
- Normalise the conversation....we talk to all yp about some of the things that might change and that you need to know now you are having tx for cancer
- Assume nothing!
- Gender neutral.....Are you in a relationship?
- Are you thinking about / having any type of sex?
- Careful /sensitive assessment to establish what their situation and knowledge base is
- Ensure you do not devalue the yp’s level of intelligence
- Tailored to the appropriate developmental level
Can I have sex?
Can I have sex if I have chemo?
  - Traces of chemo in body fluids for up to 2 weeks??
  - Platelets – risk of bruising/bleeding
Can I have sex during radiotherapy?
  - Feeling very tired
Can I have sex if I’ve had a BMT?
  - Especially vulnerable to infection for at least 6 months after.
Can I have oral sex?
  - Advise that they avoid oral sex for 5 days after last chemo
  - Advise that they shouldn’t have oral sex if they/their partner has cuts on their mouth.
  - Advise that if they/their partner has cold sores or genital herpes, these can be transferred from the mouth to the genitals and vice versa – E.G.
  - Advise them to avoid if they/their partner has thrush either on genitals or mouth.

What do we need to discuss with YP?

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Can I have anal sex?

- Yes, however if their platelets are less than 50 it is advisable not to have anal sex due to the risk of bleeding.
- If their neutrophils are less than 0.75 – not advisable due to infection risk.
- Advise them that if they would like to have vaginal sex after anal sex it is very important to use a new condom – so bacteria is not transferred.
- Anal douching is not advised as it washes away protective mucous in rectum leaving them more open to infection, also can cause irritation and tiny injuries – infection.
- Advise them about the use of oil based lubes to prevent friction/tissue damage/infection.

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The chat continued

- What if I am GLBT
  - The same issues apply
  - Sometimes yp are worried about asking for advice – may fear being judged / may only just be coming to terms with their sexual orientation
  - Just because they have had 1 same sex relationship doesn’t necessarily mean they are gay.

- Contraception
  - Medical team discuss contraception and may start yp on hormonal treatment to stop periods to reduce bleeding risk
  - This should not be considered a reliable form of contraception
  - Importance of NOT becoming Pregnant whilst on treatment.

- Fertility
  - Separate discussion (chemo side effects)
  - Sperm banking ‘chat’

- Bleeding
  - Advice re anal and rough sex

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Males - inability to keep an erection
- As a result of damaged nerves and blood vessels to penis or low levels of testosterone – radiotherapy/surgery to testicles or pituitary gland.

Females - vaginal dryness
- Due to low levels of female hormone oestrogen – Durex lubes.
- Periods may become irregular or stop – usually come back after chemo – Menopause may start younger.
- More likely to get vaginal infections – barrier protection, cotton underwear.

General side effects
- Lowered interest in sex
- Affect of pain on sex drive
- Position after surgery on a limb etc.

Emotional effects
- Body Image
- Starting a relationship can be scary!
- Discuss/talk to partner
- Support
STI risk in TYA’s with Cancer

- Greater physiologic susceptibility for STI’s due to a cluster of risk factors (compromised immune system, cognitive, behavioural, psychological factors specific to TYA’s with cancer (Murphy et al 2012))

- Bacterial STI’s such as Chlamydia and Gonorrhoea, can have an enhanced impact on pts who are already neutropenic or have renal/respiratory distress

- Long term effects of STI’s impair the ability of the immune system to operate in the usual way, enhancing chemo’s impact on healthy white blood cells & increasing risk of infection, clotting & O₂ intake.
In England alone between 2010 and 2011 there were 426,827 new infections in a 12-month period which included:

- Chlamydia: 186,196. Most of these were people aged 24 or younger
- Genital herpes: 31,154
- Genital warts: 76,071
- Gonorrhoea: 20,965. The highest rates of gonorrhoea are seen in women aged 16-19 and men aged 20-24
- HIV: 6,280
- Infectious syphilis: 2,915

Source: HPA - based on diagnoses between 2010 and 2011 in sexual health clinics in England
- Form a relationship
- Address the topic Away from parents
- Confidentiality
- Timing
- Normalise
- Educate
- Resources
- Document discussion

FACTNERD
A tool to help HCP’s address sexuality issues in YP with cancer
Behaviours: age 13 to 17

All green, amber and red behaviours require some form of attention and response. It is the level of intervention that will vary.

What is a green behaviour?

Green behaviours reflect safe and healthy sexual development. They are:
- displayed between children or young people of similar age or developmental ability
- reflective of natural curiosity, experimentation, consensual activities and positive choices

What can you do?

Green behaviours provide opportunities to give positive feedback and additional information.

Green behaviours
- solitary masturbation
- sexually explicit conversations with peers
- obscenities and jokes within the current cultural norm
- interest in erotica/pornography
- use of internet/e-media to chat online
- having sexual or non-sexual relationships
- sexual activity including hugging, kissing, holding hands
- consenting oral and/or penetrative sex with others of the same or opposite gender who are of similar age and developmental ability
- choosing not to be sexually active

What is an amber behaviour?

Amber behaviours have the potential to be outside of safe and healthy behaviour. They may be:
- of potential concern due to age, or developmental differences
- of potential concern due to activity type, frequency, duration or context in which they occur

What can you do?

Amber behaviours signal the need to take notice and gather information to assess the appropriate action.

Amber behaviours
- accessing exploitative or violent pornography
- uncharacteristic and risk-related behaviour, e.g. sudden and/or provocative changes in dress, withdrawal from friends, mixing with new or older people, having more or less money than usual, going missing
- concern about body image
- taking and sending naked or sexually provocative images of self or others
- single occurrence of peeping, exposing, moaning or obscene gestures
- giving out contact details online
- joining adult-only social networking sites and giving false personal information
- arranging a face to face meeting with an online contact alone

What is a red behaviour?

Red behaviours are outside of safe and healthy behaviour. They may be:
- excessive, secretive, compulsive, coercive, degrading or threatening
- involving significant age, developmental, or power differences
- of concern due to the activity type, frequency, duration or the context in which they occur

What can you do?

Red behaviours indicate a need for immediate intervention and action.

Red behaviours
- exposing genitals or masturbating in public
- preoccupation with sex, which interferes with daily function
- sexual degradation/humiliation of self or others
- attempting/forcing others to expose genitals
- sexually aggressive/exploitative behaviour
- sexually explicit talk with younger children
- sexual harassment
- non-consensual sexual activity
- use of/acceptance of power and control in sexual relationships
- genital injury to self or others
- sexual contact with others where there is a big difference in age or ability
- sexual activity with someone in authority and in a position of trust
- sexual activity with family members
- involvement in sexual exploitation and/or trafficking
- sexual contact with animals
- receipt of gifts or money in exchange for
How comfortable are you talking to adolescents?

What are your feelings/beliefs about adolescent sexuality?

Are you able to separate your own values in order to treat your patient?

How do you react when confronted with a patient situation that does not fit your expectations?

Does the situation provoke feelings of anxiety and discomfort?

Are you able to assess what is going on within yourself as well as within the patient?

Looking to the future.......Is it ok for HCP’s to ignore the issues & hope for the best?

- Written information.
Conclusion

- It has clearly been established that addressing the sexual health information needs of TYA’s with cancer is inadequately explored in research and within published literature.

- Research in imperative.

- Reluctance towards discussion by HCP’s, coupled with typical risk taking behaviours in this unique patient population, poses significant risk to this vulnerable demographic.

- HCP’s must strive to provide specialist care, and have a clear understanding of this age group.

- Supporting these pts is challenging, nevertheless, if these yp are to function effectively and receive expert holistic care, then HCP’s must boldly confront the barriers, implement successful interventions & ultimately stop ignoring this sensitive but crucial problem!

Beth McCann 29/10/13
Thank you for listening

beth.mccann@uclh.nhs.uk
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Royal College of General Practitioners and Brook. (2000) Confidentiality and Young People: Improving Teenagers’ Uptake of Sexual and other Health Advice. London: Royal College of General Practitioners and Brook. Beth McCann 29/10/13


