Addressing Sexuality

This document forms part of the Sexuality Section of the E-Learning Module in Paediatric Palliative Care. It may also be helpful reading for professionals working primarily with adults.

Barriers to Communication

Sexuality remains a very private and sensitive topic in most cultures today. As individuals, we all vary in the degree to which we feel comfortable to openly discuss sexual themes with important others in our lives. It is therefore not surprising that it can at first feel difficult to raise the topic of sexuality during clinical consultations. In fact, health care professionals consistently rate sexuality as one of the most difficult areas to speak about with their patients alongside spirituality and death & dying.

Some of the common factors contributing to this difficulty experienced by professionals are:

- lack of clarity about whether it is their role
- lack of knowledge & confidence, feeling deskillied (HCP often erroneously feel they need to know all the answers before being able to raise the topic)
- Uncertainty whether anything can be done
- Fear of offending the patient or making them feel worse by naming the topic
- Lack of time
- Lack of clarity about legal contexts surrounding young people and sexuality
- Assumptions (e.g. patient too young/too ill/ doesn’t have partner, already knows everything, etc.)

Unfortunately, many young patients find it just as difficult to raise the subject for a variety of reasons, eg

- generally being reluctant to talk to adults about “stuff”
- not knowing what words to use or how to start conversation
- feeling embarrassed
- not wanting to be seen as inexperienced
- not knowing if this is the “right” professional to talk to
- not knowing that what they are going through is “normal”
- not wanting to be judged
- not knowing that anything could be done to help
- being worried about confidentiality

Given these obstacles to communication, it is crucially important that health care professionals are educated about the important role intimate relationships and sexuality play in determining health outcomes and quality of
life. They should be offered training on discussing sexual matters with patients and given ready access to appropriate resources for support. Such support may come in the form of information materials, professional support forums and access to further training if desired.

Despite their sensitive nature, sexual difficulties are predictable side effects of chronic and life threatening illness and their treatment. The identification of sexual concerns is therefore an important part of the professional’s role and sexual concerns should be assessed in the same way other developmental issues, side effects of treatments and symptoms and consequences of disability and are discussed.

**PLISSIT Model (Anon, 1974)**

**Importance of Permission Giving (PLISSIT)**

PLISSIT remains a useful model to conceptualize the different layers of professional input which may be required to help patients to resolve sexual difficulties. The model emphasizes that every health care professional shares the responsibility to help create the circumstances in which patients feel more comfortable to discuss concerns of a sexual nature by communicating clearly that

- Having conversations about sexual concerns is part of the remit of the service
- Sexuality is seen as important and patients will not be judged for having sexual concerns
- The service is offered confidentially (be clear about limitations of confidentiality & where to get confidential help if not in current setting)
- Help is available
These messages can be communicated in a variety of ways which may not solely rely on verbal communication (e.g. clues in the environment, e.g. posters, display of books or video material, written patient information). It is further helpful to use holistic screening tools which include sexual and relationship topics and to integrate the naming of sexual function as a topic routinely mentioned as part of at least one standard consultation or other meeting with patients. This so-called “permission-giving” (P) is best seen as an on-going process rather than a once off event and is best not left to the discretion of only one team member.

Having received such permission to be a sexual human being and to have sexual concerns without being judged, patients are more likely to feel able to raise any sexual concerns on their mind or to answer questions of a sexual nature more openly and confidently. In some instances, permission giving and the provision of limited information may prevent difficulties from arising in the first place. These low intensity interventions by themselves can also mobilize patients’ inner coping resources to overcome some concerns by themselves.

Is that all (P-LISSIT)?

PLISSIT emphasizes that Health Care Professionals should not be expected to work above their personal comfort or skill level in this field. While there is a shared core responsibility to ensure permission giving, the individual practitioner may choose not to move beyond this level of intervention in their own work. It is therefore a related responsibility of each Health Care
Professional to ensure they are aware of who to hand over to for more detailed discussion or intervention at the next level of intervention.

Most sexual concerns are addressed successfully by the giving of limited information (e.g. STIs, risks of pregnancy, sexual side effects of treatment) or specific suggestions (use condoms & where to get them, spend more time of foreplay, try different positions).

- At least one person per setting should take on the further role of providing limited information (I) and maybe moving onto making an assessment detailed enough to provide specific suggestions (SS) to the patient. Examples of information and specific suggestions are given later in this section.
- Most sexual concerns can be addressed at the limited information & specific suggestion level of intervention.
- Only small numbers of patients require further specialist help (intensive therapy - T). Where specialist investigation, treatment of other form of intervention (GUM/Sexual Health or Psychosexual Therapy) is required, patients should be signposted/referred to the appropriate service.

Sexual Communication Skills

- The communication skills required to discuss sexual concerns are not fundamentally different from the Advanced Communication Skills package and rely primarily on expert use of basic listening and counseling skills.
- **Key Difference**: To order to help patients overcome their anxiety of raising sexual problems it can be helpful to find respectful and appropriate ways of enquiring about sexual themes in a more direct manner than usually practised.
- Gentle direct questioning communicates that such material is appropriate for discussion, without leaving a patient feeling forced to disclose information they do not wish to share (Permission Giving).

What to Say

The following are some examples of how sexual topics may be introduced into a conversation:

- “Do you have a partner at the moment/are you going out with/seeing anybody/ is there anybody special in your life at the moment?” ….. “How are they coping with the illness?”….”Has your relationship been affected in any way by the illness?”... “Has it affected the ways in which you are intimate together? Has it led to any problems sexually?”
• “I’m not sure how far you have already taken things intimately as a couple, but many people who have an illness like you find that it can really get in the way. Have you found any difficulties like that?”

• “Often, after many treatments or disease progression, a young person’s thoughts about him or herself and relationships, including sexual relationships, may be affected by treatment or their side effects. Sometimes an illness can affect relationships, especially when you don’t have enough time to hang out with your friends. How has your illness affected your thoughts about your relationships, sexual or non-sexual, between you, your friends and/or your partner?”

• “Many young men/women experience fatigue, feel unhappy about the way they look or experience other side effects, some of which affect sexual functioning, that can have an impact on their relationships. There are a variety of things we can suggest in these circumstances. Would you like to talk about any concerns like that and what you can do to manage issues related to sex or relationships?”

• “Many people your age have questions about sexuality or relationships. It can be even more difficult when you have an illness like this/are stuck in a place like this and you don’t get to spend as much time with your friends as you would like and you might not get as much of an opportunity to find out about this kind of thing. We often talk to young people about their worries about relationships or sex and we can also advise on things like safe sex and contraception.”

• “Other teenagers I work with often wonder about…”

General comments:

• Ideally, develop collaborative relationship with parents
• Depending on age and level of independence & understanding, discuss how confidential information will be handled.
• Know law around privacy and sex education & provision of sexual health services for minors (see other sections in this module)
• Build supportive relationship with patient, treat them as independent and self-responsible
• Naming of sexuality as a legitimate topic can be helpful in early/induction meetings where young person and parents are present
• Consider offering sexual resource list, naming one professional as the “sexual health expert” but making it clear that everybody else on the team can also be approached for support
• Offer opportunities to speak to patient on their own as well as with parents or partner depending on context
• Use proper terminology for sexual parts, actions and problems, possibly also offering some alternative, more colloquial words. Check patient’s understanding and knowledge.
• Clarify meaning of terminology used by young person, for example they may say they are not “having sex” whilst regularly engaging in oral sex
• Consider adjusting to language used by young person – some will find this helpful and informal whereas others may dislike an adult using “their words” – ask
• Do not make assumptions about sexual orientation – use neutral language, e.g. “partner” “the person you’re with” , “are you dating/seeing anyone?” instead of making reference to “boyfriend/girlfriend”
• Check knowledge of reproduction and sexual activity, desire for sexual information, self image, current relationships, understand how sexuality was expressed and pleasure was achieved before, if there are any problems/changes and what the wish for the future is,
• Can be helpful to assess age and stage of development and if there is deviation from expected norms
• Please refer to other sections in this module for further Information & Specific Advice (P-LISSIT)

Useful Resources:

• Books


