Sexuality in hematological patients
Nursing and psychosocial aspects

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US scientists discovered that:

• Men think about sex 19 times a day

  • Almost 8,000 times less than previously thought.
  • They also think about food almost as much as sex - 18 times a day.
  • Closely followed by sleep, which crosses their mind 11 times a day.

• On average, men still think about sex twice as much as women
Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.

Each patient defines their sexuality and sexual health differently and uniquely according to gender, age, personal attitudes, and religious and cultural beliefs.


National Cancer Institute, 2006
A complex problem!

- History of patient → Previous treatments that affect sexuality
- Disease
- Treatment
- Follow up

- Haematological disease / malignancy
- The side effects that directly and indirectly affect sexuality
- The short and long term effects
- .... the future life
The side effects of treatment

**Chemotherapeutic Agents**
- Amenorrhea
- Premature menopause
- Erectile dysfunction
- Azoospermia or oligospermia
- Decreased libido
- Potential for drug to be excreted in human milk

**Radiation Therapy**
- Ovarian failure (causing infertility or sterility)
- Premature menopause
- Amenorrhea
- Painful intercourse
- Loss of libido
- Decreased lubrication
- Vaginal atrophy
- Vaginal stenosis or shortening
- Testicular aplasia (leading to infertility or sterility)
- Erectile dysfunction
- Chronic diarrhea
- Chronic fatigue
The side effects of treatment

Stem Cell and Marrow Transplant
- Decreased sexual desire and satisfaction
- Vaginal atrophy
- Decreased lubrication
- Painful intercourse
- Premature ejaculation resulting from prolonged abstinence
- Impotence or erectile dysfunction
- Body image changes
- Chronic fatigue
- Chronic gastrointestinal disturbances
The side effects of treatment

Changes in:

- Body image
- Reproductive function
- Sexual function

= All aspects of cancer and cancer treatment may affect human sexuality
(Krebs, 2006)
What are patients asking for about sexuality?

Several patients stated that they wished they had simply been asked about their sexuality by their nurse.

Others wanted to know that it would have been okay to ask their nurse questions about sexuality.

“if my nurse had brought up the topic of sexuality, it is possible I would have found it interesting.”

Information regarding what happens to the body during cancer treatment and the impact fatigue has on sexuality would have been appreciated.
What are patients asking for about sexuality?

- Permission
- Normalising and validating
- Information
- Practical advice and appropriate referral
How to start?

Be aware of your **own attitudes** and **knowledge** about sexuality!

➔ *Nurses should find their own comfort zone for making this assessment in their patients.*

Avoid missing opportunities to discuss sexuality.

**Assessment** of sexual health is the first part of problem identification

(Julien, Thom, & Kline, 2010)
Two communication tools to address sexuality:

- **PLISSIT model**
  Is a four-step model. A systematic approach to learning about a patient’s sexual concerns and discussing supportive interventions based on four sequential intervention levels requiring increasing knowledge and expertise (Annon, 1976; Katz, 2005).

- **BETTER model**
  Was developed specifically for oncology nurses. Employs a step-wise sequence to help facilitate communication between patient and nurse about the sensitive issues of intimacy, sexuality, and sexual dysfunction (Mick, 2007; Mick, Hughes, & Cohen, 2003, 2004).
Assessment

**PLISSIT model**
- **P** = Permission
- **LI** = Limited Information
- **SS** = Specific Suggestions
- **IT** = Intensive Therapy

**BETTER model**
- **B** = Bring up the topic
- **E** = Explain to the patient
- **T** = Tell the patient
- **T** = Time of the discussion
- **E** = Educate the patient
- **R** = Record the elements
Assessment

Two models to assess sexual function (Krebs, 2006; Mick, 2007):

**ALARM model and PLEASURE model**

**PLEASURE** (Schain, 1988)
- Partner
- Lovemaking
- Emotions
- Attitude
- Symptoms
- Understanding
- Reproduction
- Energy

**ALARM** (Andersen, 1990)
- Activity
- Libido
- Arousal
- Resolution
- Medical information (cancer and health status)
Assessment

- Patient history
- Patient coexisting variables
- Type of hematological disorder
- Bring up the topic
- Discuss and check fertility issues
- Encourage Questions About Sexuality

For instance start with less sensitive questions and move toward more sensitive ones.
## Example assessment (Post - HSCT)

### Vrouwen

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.6. Heeft u last van een verminderd seksueel verlangen sinds de stamceltransplantatie?</td>
<td>Nooit, Zelden, Soms, Vaak, Altijd</td>
</tr>
<tr>
<td>9.7. Heeft u last van vaginale droogheid?</td>
<td>Nooit, Zelden, Soms, Vaak, Altijd</td>
</tr>
<tr>
<td>Indien nooit, ga verder naar vraag 9.9.</td>
<td></td>
</tr>
<tr>
<td>9.8.1. Zo ja, Geef de score aan op de schaal die overeenstemt met uw gemiddelde pijn tijdens het seksueel contact.</td>
<td></td>
</tr>
<tr>
<td>Score 0 betekent geen pijn 😊 en score 10 betekent onuitstaanbare pijn 😞.</td>
<td></td>
</tr>
<tr>
<td>9.9. . Heeft u nog uw maandstonden?</td>
<td>Ja, Neen</td>
</tr>
<tr>
<td>Zo neen, ga verder naar vraag 10.1.</td>
<td></td>
</tr>
<tr>
<td>9.9.1. Zo ja, zijn de cycli regelmatig (tussen de 21 en de 35 dagen)?</td>
<td>Ja, Neen</td>
</tr>
</tbody>
</table>
### Mannen

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.2. Heeft u last van een verminderd seksueel verlangen sinds de stamceltransplantatie?</td>
<td>Nooit, Zelden, Soms, Vaak, Altijd</td>
</tr>
<tr>
<td>9.3. Heeft u erectieproblemen?</td>
<td>Nooit, Zelden, Soms, Vaak, Altijd</td>
</tr>
<tr>
<td>9.4. Heeft u pijn bij ejaculatie?</td>
<td>Nooit, Zelden, Soms, Vaak, Altijd</td>
</tr>
<tr>
<td>9.5. Heeft u pijn bij seksueel contact?</td>
<td>Nooit, Zelden, Soms, Vaak, Altijd</td>
</tr>
<tr>
<td><strong>Indien nooit, ga verder naar vraag 9.6.</strong></td>
<td></td>
</tr>
</tbody>
</table>

#### 9.5.1. Zo ja, Geef de score aan op de schaal die overeenstemt met uw gemiddelde pijn tijdens het seksueel contact.

*Score 0 betekent geen pijn 😉 en score 10 betekent onuitstaanbare pijn 😞.*

<table>
<thead>
<tr>
<th>Score</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
Example 1

Young male patient (17 years). hospitalized for starting treatment. After discussion impact on fertility has chosen to preserve a sperm sample for the future.

‘I never felt in my life such a humiliation as the moment I had to donate sperm’

Why was this?
• No suitable accommodation.
• Mother was waiting outside!
• The handling of the semen sample.
Example 1: possible nursing interventions

- Customized information
- Adapted accommodation (room, wipes, towels, ...)
- Foresee privacy (auditory and visual privacy)
- Timing (not during visiting hours!)
- Trade professionally
- Discuss fears
- ...
Example 1: possible nursing interventions
Example 1

Young male patient. First day starting treatment on day hospital. Mother was very worried. There was nothing said about fertility.

Why was this?
• The doctor had not mentioned because the treatment has no lasting effect on fertility.

Solution:
To address the doctor to discuss this issue before starting treatment.
Example dismissal brochure

Sexual Activity

Patients may resume sexual activity with a single healthy partner once their platelet count is greater than 50,000. We recommend the use of male or female condoms with lubrication and avoidance of performing oral or anal sex for six months following HSCT. We encourage patients to discuss low libido, dyspareunia, and erectile problems with their healthcare providers. Dyspareunia may be a symptom of chronic GVHD of the vaginal mucosa or menopause, and low libido and erectile problems may indicate hypogonadism.

Vaccinations

Although it is not always possible to ensure vaccination, efforts should be made to vaccinate against diseases that are common in the area during daylight hours.

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The Faculty and Staff of the Stanford BMT Program.

Note. Figure courtesy of the Stanford Blood and Marrow Transplant Program. Used with permission.
"I'm glad you ask. I find it hard to tell anything about this to the doctor."

I really would not know if i can get an erection. It's definitely been over a year since we made love.

"What are you asking about! That is not a priority. First recover and we'll see."

"This is not easy, but I'm glad I can discuss with you."

"It's been long since we made love. But I once masturbated and when I came it was painful. Since then I've no more! I'm afraid!"
Take home massage

- A discussion regarding sexuality can be uncomfortable for both nurses and patients.

- Communication tools such as PLISSIT or BETTER can help nurses gain confidence in their abilities to address sexuality.

- Use as a nurse this (confidential) position in its ability to discuss care for sexuality and intimacy.
Take home massage

• Recognize the patient as a sexual person
• Emphasize importance of intimacy
• Sexuality and intimacy remain debatable!
• Stimulate discussion about the possible changes
• Attention to the partner!
Questions

let's also talk about sexuality!