Have a Seat at the Sex Café: Discussing and Managing Intimacy Concerns and Sexual Symptoms in Patients with Serious Illness

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Objectives

- Describe the existing evidence base on intimacy and sexual symptom assessment and treatment in the palliative care population.
- Perform an intimacy and sexual symptom screening and assessment.
- Identify medical, psychological, and social issues leading to intimacy and sexual symptom concerns in patients with serious illness.
- Develop a treatment plan to address intimacy and sexual symptom concerns in a patient with serious illness.
• Sexuality and Intimacy have been identified as important components of a palliative care (PC) assessment

• Evidence shows that patients want to discuss issues around intimacy/sexuality

• Yet intimacy and sexuality are not routinely assessed for inpatient PC consults
Defining Sexuality & Intimacy

- Qualitative study explored the meaning of “sexuality” among palliative care patients:
  - “Emotional closeness”; intimacy
  - Physical expressions – often activities other than intercourse
- Consider a broader, more subjective (i.e., patient-centered) definition of sexuality

Lemieux et al., 2004
Preferred Practice

- National Quality Forum (NQF) preferred practices guidelines for hospice and palliative care:

  “a social assessment plan should address sexuality/intimacy, an area frequently overlooked in social planning”
I asked my cardiologist about any treatments that could help, and he said I shouldn’t be focusing on “that” right now.

When I asked the doctor for Viagra he told me first to check and see if my wife was interested in “That”

My doctor asked me if I was “active” and I told her sure I work out a few times a week. Then she laughed.
Existing Evidence
Available Models For Assessment

- ExPLISSIT (Taylor & Davis, 2006)
- PLISSIT (ANNON, 1976)
- BETTER (Mick & Cohen, 2003; Mick et al., 2004)
- ALARM (Andersen, 1990)
Barriers To Assessment

• Inadequate clinical training

• Lack of time

• Misconceptions about the importance of sexuality/intimacy in the seriously ill (he is too old, too sick, not in a relationship etc..)

• Patients will raise the topic if it is a concern (if it was important they would ask)
Medical School Education

- **Objective Information:**
  - How many partners have you had in the last year?
  - Are your partners men, women, or both?
  - Do your sexual encounters include oral, anal or vaginal sex?

- **Assessing Risk**
  - Most questions asked to assess for risks related to sexual transmitted diseases

- **You may ask male patient if they have difficulty achieving erections.**
  - But even this is to partially to assess for vascular disease.
Social Work Education

- Largely institution based
- Focused on prevention of sexually transmitted diseases, and teenage pregnancy
- Little focused on intimacy and sexual health within the aging population
- Even less for end of life care
PharmD Education

- Included as an element in patient history taking
- Mostly aimed at assessing risk of sexually transmitted diseases
- Teaching patients how to use OTC contraceptives
- Recommending appropriate prescription oral contraceptives and providing related patient counseling
GENTLEMEN:

VIAGRA helps guys with ED
get and keep an erection.
What we set out to do...

• We wanted to understand:
  • If intimacy was an important issue for hospitalized PC patients
  • How intimacy was impacted by illness
  • If intimacy concerns were present, what those concerns involved
Assessment Tool

<table>
<thead>
<tr>
<th>How much has your illness affected intimacy?</th>
<th>None</th>
<th>Little</th>
<th>Moderately</th>
<th>Significantly</th>
<th>Declined to respond</th>
</tr>
</thead>
<tbody>
<tr>
<td>How has your illness affected your relationships (partner, children, grandchildren etc...)?</td>
<td></td>
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</tbody>
</table>

Has this been discussed before during your hospital stay? □ Yes □ No
Is this helpful to talk about? □ Yes □ No
Methods

• Design:
  • Quality Improvement Initiative
  • Assessment Tool for Intimacy/Sexuality

• Sample:
  • Inpatients receiving PC consultation
  • Capacitated
  • Adults 18 and over
Methods

• Setting: two inpatient hospital sites
  • Large (>900-bed) tertiary care academic medical center
  • Small (<200-bed) community-based hospital

• Analysis:
  • Self rated assessment
  • Compared EOL and those not at EOL
## Results
**(n=57 inpatient PC consultations)**

### Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age (yrs)</td>
<td>58</td>
</tr>
<tr>
<td>Male</td>
<td>60%</td>
</tr>
<tr>
<td>Race</td>
<td>68% AA</td>
</tr>
<tr>
<td>Relationship status</td>
<td>Spouse 44%</td>
</tr>
<tr>
<td></td>
<td>Single 35%</td>
</tr>
<tr>
<td></td>
<td>Significant Other 21%</td>
</tr>
<tr>
<td>Average time in relationship</td>
<td>24 years</td>
</tr>
<tr>
<td>(n=22)</td>
<td></td>
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### Disposition of Patients Following Hospitalization

- **Home**: 63%
- **NH**: 5%
- **AMA**: 4%
- **Death**: 11%
- **Home hospice**: 18%

![Disposal of Patients Following Hospitalization](chart.png)
End of Life (EOL) is defined as patients that died 3 months after initial PC consult
How much has your illness affected intimacy?

Full Sample

<table>
<thead>
<tr>
<th>Percent</th>
<th>Significantly</th>
<th>Moderately</th>
<th>Little</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>35</td>
<td></td>
<td>20</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td>0</td>
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</tbody>
</table>

- Significantly
- Moderately
- Little
- None
How has your illness impacted intimacy?

- Significantly
- Moderately
- Little
- None

Not EOL
EOL

Percent

Significantly
Moderately
Little
None

[Graph showing percentage of responses for each level of intimacy impact for both Not EOL and EOL patients]
Identified Issues

Largely related to sexual health

- Low libido (26%)
- Erectile dysfunction (35% among only male patients)
- Lack of privacy (7%)
Identified Common Themes

- Issues around sexual health were raised
- No one was asking about intimacy/sexuality
- Initiating and continuing the discussion was important
- Broken down into six common categories
Difficulties Finding New Relationships

• “It is hard to find someone when you are sick.”

• “I don’t have a partner now, but I would like one and I’m not sure how to find or get into a relationship because of my illness.”

Kelemen et al..
Altered Body Image

• “I lost a lot of weight and my breasts got very small.

• I don’t like my stomach when I have all this fluid.
Weakness/Fatigue

- “I often feel too tired for sexual intercourse and I am worried about my heart and sex.”

- I feel too weak to be physically intimate and I feel bad for my partner. We talk about it and she tells me not to worry, but I do.
“I’m embarrassed at how many pills I take. I felt ashamed and I was worried if he found out how sick I am he would leave.”

“I was not open with previous partners about my illness because of fears around rejections. I’m more open now in my current relationship.”
Illness Limits Activities with Loved ones

- “I worry with my grandchildren, when they run towards me. I now pause because I’m afraid they may run into my lines, tubes, bags, etc.”

- “Since my illness [my functionality] has declined, I am no longer able to drive my grandchildren to school.”
Changes in Physical Intimacy/Closeness

- Yes [the illness] has affected relationships, I feel like I’m back to being a “boy” It’s taken away my “manhood.”

- We now sleep in different rooms because of my illness. I spend less time with my partner and I am in the hospital a lot.
Case

- 60 year old male s/p LVAD with multiple complications. In the hospital for several months. His wife asks “I’m not sure who to talk to about this, but it appears that my husband’s libido has resurfaced.”

- Patient is in the hospital, not expected to be able to go home.

- Wife is asking for some time alone with her husband
Barriers

- Hospital Staff
- Consent
- Medications
Treatment Options

• Rule out reversible/modifiable medical causes
  ○ Hypogonadism, cardiovascular disease, hypertension, diabetes mellitus (DM), tobacco use, hyperlipidemia, lower urinary tract symptoms, metabolic syndrome, and depression

• Patient centered options
  ○ Strategies for privacy
  ○ Education on safety and barriers for physical activity
  ○ Supporting the patient/provider communication
• Lubricants are generally safe and well tolerated
• Localized estrogen therapy may be contraindicated in certain disease states (breast and gynocological cancers) and can increase risk of blood clots
• Phosphodiesterase-5 inhibitors (PDE5Is)
  ○ avanafil (Stendra)
  ○ sildenafil (Viagra)
  ○ tadalafil (Cialis)
  ○ vardenafil (Levitra, Staxyn)
  ○ CAUTION: Do not use these ED medications if you take nitrates, such as nitroglycerin or a similar medicine, for chest pain. The combination can cause dangerously low blood pressure.
Medications (De-prescribing)

- Diuretics/ HTN meds/ Antiarrythmics
- Antidepressants and anti-anxiety drugs
- Antiepileptic drugs
- Antihistamines
- Non-steroidal anti-inflammatory drugs
- Parkinson's disease medications
- H$_2$-receptor antagonists
- Muscle relaxants
- Anticancer meds

- Alcohol.
- Amphetamines.
- Barbiturates.
- Cocaine.
- Marijuana.
- Methadone.
- Nicotine.
- Opiates.
Why Doctors May feel Uncomfortable

- A qualitative sexual history, while medical, may be outside typical training for a physician
  - Doctors may be afraid to broach a topic that they don't feel they have good solution to – Medicine is often too focused on “fixing” problems.
  - Even in Palliative Care, time demands on physicians are plenty and a physician may fall into the habit of focusing mostly on classically 'higher yield' questions about symptoms
Initiating Discussion

• Assess comfort

• Normalize the issue

• Listen

• Respond/provide recommendations when necessary
Documentation
Next Steps

• Next steps could include questions about sexual health

• Recommendations regarding management strategies

• More qualitative studies specific to PC needed
  • Approval for qualitative study recorded interviews with patients.
Questions
References

- Nyatanga, B. Sexuality in palliative care: more than sex. British J of community nursing 201419, (3)151.
References