Sexuality & Intimacy within the Context of Life-Threatening Illness

Implications for hospice and palliative care professionals

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Presentation Objections

1. Define "sexuality" & "intimacy"
2. Discuss importance of sexuality/intimacy
3. Identify obstacles & opportunities to supporting expressions of intimacy/sexuality
4. Review strategies for broaching the subject with patients/families
5. Present targets for assessment & intervention
“We must grapple with the fact of our own mortality and the realization that intimacy occurs in the face of eventual loss.”

- John S. Rolland
Defining Sexuality & Intimacy

• What exactly is meant by “sexuality”?  
  – Sexual orientation?  
  – Sexual health?  
  – Only relevant in the context of couplehood?

Defining Sexuality & Intimacy

• Sexuality, noun, [ˌsekSHooˈalədē]:  
  – Capacity of sexual feelings  
  – A person’s sexual orientation  
  – Sexual activity

Oxford English Dictionary
Defining Sexuality & Intimacy

• Intimacy, noun, [ˈɪn(t)əməsē]:
  – Close familiarity or friendship; closeness
  – A private cozy atmosphere
  – An intimate act, especially sexual intercourse

Oxford English Dictionary

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
Our Patients are Diverse!

- Extramarital expressions/poly-amorous
- Celibacy/abstention/asexuality
- LGBTQ
- Autoerotic practices

- Clinicians must acknowledge their own beliefs, biases, and prejudices!!!
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”

An Avoided Conversation

“Various devices and rationalizations are used [by clinicians] to avoid dealing with the sexual concerns of those with whom they work”

-Harvey Gochros
The “Double-Barreled Taboo”

- A vast societal discomfort with mortality and sexuality

Jaffe, 1977

Obstacles to Communication

- Barriers to these conversations include:
  - Inadequate clinical training
  - Lack of time
  - Fear of being intrusive
  - Underestimating the significance
  - Assume patients will raise the topic
Obstacles to Communication

• Assumed not important due to patient:
  – Age
  – Diagnosis
  – Relationship Status
  – Culture

Lack of Assessment

• Among hospice psychosocial assessments:
  – >2/3 of assessments did not include items exploring issues related to intimacy/sexuality
  – Issues of intimacy were included in 31%; sexuality only 9%

Cagle et al.
Discussions are Needed/Wanted

- Among palliative care patients – 71% at end of life (<3 mos) reported their illness had significantly or moderately impacted intimacy

- 100% indicated that clinician led discussions about intimacy/sexuality were helpful

Keleman, Cagle & Groninger, in press

Patients want to have the Conversation

- Many patients with life-threatening illness want to discuss issues related to intimacy, sexuality and their disease
Communication Basics

• Sexuality/intimacy should be routinely assessed
• Clinicians should initiate the topic
• Be nonjudgmental; explore personal bias/values
• Work within the family’s value system (start where they are).

Communication Basics

• Pay attention to the environment; make sure it’s conducive to discussion
• Listen; use attending behavior
• Empathy
• Empower patients/families to bring up the subject
• Maintain a relaxed attitude
• Use open-ended questions; invitations to talk
Communication Basics

• Let patients/family members know they are not alone

• Frame worries about sexual issues as normal, legitimate health concerns

Communication Basics

• Provide education
• Use clear, nontechnical language, and avoid medical jargon
• Address the myths and misconceptions – e.g., fears that cancer is contagious
Older Adults & Sexuality

• Older adults continue to have:
  – Physical urges
  – Sexual intercourse
• Shift from physical displays to emotional closeness
• Sexual function may be diminished

The Voices of Patients

• Qualitative data re: intimacy concerns of palliative care patients
• Mainly heart failure dx
• Roughly 1/3 discharged to hospice
The Voices of Patients

• 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”

Keleman, Cagle & Groninger, in press

The Voices of Patients

• Changes in Physical Intimacy/Closeness
  – “We stopped having sexual intercourse, but we were still physically intimate. After my last surgery we stopped all forms of physical intimacy. I still want to be intimate, because I feel I need a companion.”
  – “Yes [the illness] has affected relationships, I feel like I’m back to being a ‘boy’ It’s taken away my ‘manhood’”

Keleman, Cagle & Groninger, in press
The Voices of Patients

• *Changes in Physical Intimacy/Closeness*
  – “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.”
  – “I’m too sick to be physically intimate, but we find other ways, like cuddling. I do feel less adequate.”

  *Keleman, Cagle & Groninger, in press*

• *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.”

  *Keleman, Cagle & Groninger, in press*
The Voices of Patients

- **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.”

  *Keleman, Cagle & Groninger, in press*

- **Fear/Embarrassment**
  - “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.”

  *Keleman, Cagle & Groninger, in press*
The PLISSIT Approach

• The PLISSIT model:
  – Permission
  – Limited Information,
  – Specific Suggestions
  – Intensive Therapy

Annon, 1976

Permission

• Communicate willingness to discuss sexually-related topics
• Extend open-ended invitation
• Example:
  “Those in similar situations have expressed concerns about intimacy and sex. What concerns are you having?”
Limited Information

• Brief education to patients/partners regarding common sexual issues associated with an illness or treatment, including:
  – Etiology
  – Pathology
  – Complications

Specific Suggestions

• Concrete suggestions on how to cope with the effects of the illness. For example:
  – Pleasuring
  – Altering positions to minimize pain
  – Dealing with powerful emotions (guilt, resentment, anger)
  – Medication

• If the patient is partnered, it may be best to see the couple together
Intensive Therapy

- In a minority of cases, referral to a specialist (e.g., relationship counselor/sex therapist) may be warranted.

Alternate Models

- ExPLISSIT (Taylor & Davis, 2006)
- BETTER (Mick & Cohen, 2003; Mick et al., 2004)
- ALARM (Andersen, 1990)
Dimensions of Assessment & Intervention

• 1. Body image and self-concept
• 2. Changes in sexual functioning/desire
• 3. Social and relational concerns
• 4. Systemic barriers

Body Image & Self-Concept

– Grooming/appearance are core components of QOL
– Body image is linked to self-esteem
Body Image

- However, advanced illness is fraught with:
  - Physical issues/disease progression
    - Wasting
    - Hair loss
    - Disfigurement
    - Unpleasant odors
    - Swelling
    - Bedsores
    - Tremors
    - Possible contagions
    - Incontinence

- Treatments
  - Bandages
  - Suction machines
  - Catheters/ostomies
  - Oxygen canulas/nebulizers
Body Image – Case Example

• Patient feels less desirable post-mastectomy
  – *Normalize:* “After a mastectomy, it is not unusual for women to report higher levels of dissatisfaction with their body image”
  – *Concrete suggestions:*
    • “Perhaps wearing a bra or camisole with a prosthetic during sexual intimacy would improve how you feel about yourself.”
    • Highlight other physical attributes

• May also challenge assumptions linking breasts to self-worth/desirability
• Possible referral: www.breastfree.org
Dimensions of Assessment & Intervention

• Changes in Sexual Functioning/Desire
  – Explore alt. means of sexual expression
  – Poss. Rx intervention
  – Align expectations w/ reality

• Social & Relational Concerns
  – Relationships can strengthen at EOL
  – Facilitate social connections/family involvement
  – “Living yet to do” rather than “dying”
  – Respect privacy/intimacy
Dimensions of Assessment & Intervention

• **Systemic Barriers**
  – Change policies & institutional rules/practices that impede sexual expression, e.g.,
    • wait for permission before entering the room
    • “privacy please” signs
    • hospital beds for 2
  – Staff in-services on patient rights/intimacy needs

The Patient-Family Approach

• Don’t neglect the intimacy/sexual needs of family members
Professional Boundaries

• The clinical relationship and rapport-building are important, BUT clinicians should maintain:
  – Clear professional boundaries
  – High ethical standards
  – A patient-family directed approach

*Ask for help from the team when needed!*

One Last Time

• 71 yo AA male with terminal CA Dx, CHF, home PCA, makes a Viagra request. Patient and wife are aware of the risks.
The New Girlfriend

• A married 82 yo NH patient with dementia begins to develop a new intimate relationship with another NH resident. The wife and family are not happy...

Jack’s Request

• A dying 15 yo boy wants to experience sex before he dies. The family considers hiring a professional.
Take Home Points

• Intimacy/sexuality are important at EOL
• Hospice/palliative care professionals should consistently pay attention to sexuality/intimacy – including bringing up the subject
• Clear communication is key
• The PLISSIT model may provide a useful template for addressing these issues

Acknowledgements

• My co-authors and colleagues
  – Anne Keleman, LCSW
  – Hunter Groninger, MD
  – Sage Bolte, PhD
Thank you!

References