Sexuality: Challenges for Palliative Care Patients and their Families

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Disclosures
None

Palliative Care and Sexuality...

“I am never going to have sex again...never going to have anything like sex again. I think about it a lot and no one even asked...”
(Robert, patient, age 68)

“I am much more comfortable talking about death and dying than I am talking about sex.”
(Joan, nurse, age 59)
Aims

- To broaden our understanding of sexuality and intimacy in PC context
- To clarify connection between sexuality and quality of life in PC context
- To review common challenges for patients/partners
- To clarify straightforward language and review strategies for initiating inquiry & addressing challenges regarding sexuality/intimacy

Sexuality: What is it (we don’t talk about…)


Beyond the physical mechanics...

Sexuality is multi-dimensional
- Physiology
- Emotion
- Cognition
- Behavior
- Identity
- Body Image
- Self-Esteem

NOT just intercourse / physical encounter
What is "Normal"?

- Wide and varied range of normal functioning
- Sexuality has different meanings and levels of importance to each individual

What's the point?

- Primary goal of PC is focus on quality of life.
- Philosophy of PC is to provide holistic care.
- Aim of PC is to help patients preserve meaning and help fulfill their sense of purpose in whatever time they have remaining.
- The goal of PC is to alleviate suffering.

Sexuality/Intimacy and Quality of Life

- Reduces stress/emotional tension
- Decreases feelings of depression
- Helps maintain sense of identity
- Promotes better sleep and relaxation
- Can relieve pain/anxiety

Kelemen, et al. JPM. 2016;19(10) 1102-5
Sexuality and End of Life

- Sexuality is central to person’s sense of self throughout the lifespan
- Expressions of sexuality can be a vital form of communication that: 1) helps provide comfort and relieve suffering and 2) maintains connectedness in face of life-limiting illness
- Affirms a sense of self when other roles are lost

Sexuality: PC Core Competency

- Sexuality is a fundamental dimension of a comprehensive assessment when working with people who are critically ill (National Consensus Project for Quality Palliative Care [NCPQPC], 2004)
- National Hospice and Palliative Care Organization (NHPCO) identified the assessment of sexuality as a core competency for social workers in end-of-life care settings (Hay & Johnson, 2001).

In the Patients’ words…

Lemieux, (2004): Qualitative face-to-face interviews with 10 PC pts (hospital/hospice/home-based services)

✔ Only 2 pts alive by end of study: avg amount of time btw interview and death for other 8 pts was 5 weeks.

✔ 4 Key Domains: Meaning of Sx/Sx and QOL/Barriers to experiencing Sx in institutional setting/Discussing Sx
Results (Lemieux, 2004)

- 9/10 pts reported that sexuality and impact of illness on sexuality needed to be addressed. Only 1 pt had discussed sexuality with anyone (including his/her partner).
- Emotional connectedness taking precedence over physical; but level of importance on sexuality not significantly altered.
  - "A look across the room"
  - "Holding hands, hugging, kissing"
  - "Being physically close"

Results cont. (Lemieux, 2004)

- Sexuality IS important at end of life but pts face MANY barriers
  - Lack of privacy/shared rooms/ intrusions by staff/size of beds
- Only one patient has ever talked about sexuality with clinician; all pts wished it would have been brought up as part of care

Challenges for Clinicians...

- UK MD/Nurses study w OV CA Pts (Stead, Brown, Fallowfield, & Selby, 2003)
  - Almost all providers thought that sexual issues should be discussed; only 21% did
  - 80% of oncologists said they did not have adequate time to address this issue
- National PCP Survivorship Study (Robey, Rocklitis, Campbell, Park, Kutner, Najita & Diller, Cancer, 2009
  - 62% of PCPs rarely or never addressed issue: lack of training/preparation
What We Know…

- Terminally ill pts continue to have sexual thoughts and feelings and value opportunities to express this aspect of their experience (Redelmeier, 2008).

- Vast majority of terminal patients still want clinicians to address the topic. (Ananth et al, 2003)

- At end of life, physical closeness/shared expression of intimacy may become more important despite the mounting barriers that get in the way. Pts/partners often left to cope on their own.

Yet...there is silence

- Symptom burden at end of life: hospice staff members (16 centers) returned data on 348 pts. Goal of study: to describe symptom prevalence, frequency and severity. (Kutner et al, 2001)

- Problems with sexual interest or activity was NUMBER 1 symptoms that providers were unable to rate for over 90% of patients

When we do not address practical strategies, alterations in sense of self and relationship dynamics, the message is that these issues are 1) beyond help and 2) not important.

Barriers for Providers

(Why we don’t talk with pts about sexuality)

- Lack of practice/Lack of formal training
- Challenges in Communication
- Misconceptions about importance/relevance of sexuality to pts in PC context
- Embarrassment
- It is someone else’s responsibility
- Time constraints
- Pandora’s Box
Barriers for Patients
(Why patients don’t talk to us about sexuality)

- Fear of being judged negatively
- Challenges in Communication
- Embarrassment (including NOT wanting to Embarrass YOU)
- There are not asked!

Barriers to Communication: Multiple Levels

- Personal Barriers
  - Lack of Training/Experience
  - Feelings of discomfort, embarrassment
- Systems/Institutional Barriers
  - Lack of privacy
  - Lack of resources
- Socio-Cultural Barriers (Assumptions)
  - Age (pts are too old, too ill, to think about sex?)
  - Gender (comfort with opposite sex pt?)
  - Sexual Orientation (discomfort in taking sx hx?)
  - Status (what if single, widowed, unpartnered?)

Intervention

- The goal of intervention is to meet patients and partners where they are
- Acknowledgement and validation of loss is part of alleviating suffering
- Helping pts in PC setting have better sex is unlikely....
- Allowing pts to explore the full range of their emotional life means making room for this topic.
Starting the Conversation

• “Many pts that I see express some concern about how their illness has affected sexual function. What has this been like for you?”

• “How has your illness affected your relationship? Do you have concerns or worries that you might want some help with?”

• “In my experience, it is common to think about how sexuality changes in the context of serious illness. Is this something you would like to talk about?”

Including Partners in the Conversation...

• “Most couples find that the experience of illness strongly affects their relationship on many levels. What has this been like for you as a couple?”

• “Touch is a very important part of maintaining intimacy. Sometimes partners are worried that sexual touch might hurt and they don’t want to cause any pain. Has this been something you might have concerns about?”

Dimensions for Assessment and Intervention

• Body image and self-concept
• Changes in sexual functioning and desire
• Social and relational concerns
• Systemic barriers

(Cagle and Bolte, 2009)
Body Image and Self-Concept

- Grooming and appearance are integral aspect of sexuality; challenging with advanced disease
- Loss of body parts, loss of limbs, loss of sensation
- Scars, skin changes, surgical reconstruction
- Body weight change, unpleasant odors, bedsores, tremors, incontinence
- Ostomies, bandages, machines, catheters

Addressing the Issues...Concretely

- Minimize odors (aroma therapy, e.g. eucalyptus or peppermint oils)
- Discuss alternate positions to facilitate comfort
- Increase access to services that enhance appearance (salon care, makeup, ostomy pouches: again ask what the patient wants!)
- Problem-solving about using “camouflage”

Changes in Function and Desire

- Start by addressing medical and environmental barriers
  - Pain, fatigue, and other physical limitations
- Shift focus to pleasure/sensuality – reduces pressure, has impact on desire, allows for alternative modes of expression
- Interventions may need to be adapted
Managing Fatigue and Pain

- Important to ask how fatigue/pain affect sexuality
- Can emphasize importance of non-penetrative sexual activity (pleasure rather than “sex”)
- Encourage pt to find best time of day (more energy, less symptoms)
- Help pts and partners set realistic goals
- Use of pain meds before physical intimacy

Social and Relational Context

- Encourage partners to participate in routine care
- Need for couples to expand the repertoire
  - Finding other ways for physical, emotional closeness
  - “What kind of touch would feel best for you?”
- Need to mediate concerns about asymmetrical pleasure giving
  - Role changes/ addressing reciprocation

Broadening the Repertoire: Helping Couples Find Other Means of Expression

- Cuddling
- Holding
- Hugging
- Kissing
- Sexual fantasy
- Massage
- Tickling
- Stroking
- Scratching
- Manual genital stimulation
Acknowledging/Addressing Systemic Barriers

- Institutional care not conducive to intimate interactions! 80% of deaths in such settings...
  - Macro-level changes such as “privacy please” signs
  - Staff needing to know, wait for permission before entering
  - Hospital beds and other physical barriers need to be acknowledged (Bowden & Bliss, 2009)
    - Hospital bed decreases closeness/intimacy

Advocacy on behalf of LGBT Pts

- Many states do not guarantee family medical leave, visitation rights, custody rights and survivors benefits to those in same-sex partnerships
- Acknowledgement and advocacy for the rights of a vulnerable population at end of life can directly affect dignity at end of life as well as honor importance of relationships and self-determination (Cagle 2009)

Case Example: Joanna, Age 35

- Dx: Metastatic Gastrointestinal Stromal Tumor (GIST)
  - Diagnosed four years earlier: post-surgery, multiple targeted chemotherapeutic agents, considering available clinical trials...
  - Married for 5 years, no kids. Had been working until one year ago
  - Presenting problem: Joanna reports severe increase of menopausal symptoms, change in mood, loss of desire, after starting Lupron to address iron deficiency anemia (heavy vaginal bleeding). Anemia improved when menses ceased.
Case Example: Martin, age 67

- Dx: Prostate Cancer, Bone Mets
- On endocrine therapy (ADT) (Previously had XRT). Cancer continuing to spread
- Married, 37 years. Former Professor, now retired.
- Presenting problem: ED

DFCI Sexual Health Program

Mission: To help patients restore healthy sexual functioning as an integral part of overall survivorship care.

The SHP is a multi-disciplinary clinic that incorporates medical and behavioral approaches to successfully treat sexual dysfunction after cancer. The SHP aims to develop, evaluate and disseminate practical programs of sexual rehabilitation for a wide range of cancer survivors.

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