Intimacy as a Vital Sign in Hospice:  
A Little Regarded Aspect of Patient Wholeness

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Objectives

● Define the current state of literature regards intimacy
● Describe barriers to assessing intimacy and creating a conducive environment
● Describe roles of the interdisciplinary team
● Develop a strategy for assessing intimacy as a quality of life measure
What is Quality of Life?

In the socio-medical literature, QOL has been equated with a variety of terms:

- Life satisfaction
- Self esteem
- Well-being
- Happiness
- Health
- Value and meaning of life
- Functional status
- Adjustment

Measuring Quality of Life

- Health-related quality of life (HRQoL) is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life.

- [www.healthypeople.gov](http://www.healthypeople.gov)
Why Are We Here??????

The Sexual Revolution

- Multifactorial:
- Baby Boomers: 1945-1964
- Women entered workplace
- Birth control pill 1960
- Hugh Hefner 1950s
- Media, Feminism 1960s, Gay Rights 1969
- Social Upheaval
- Elvis Presley and Rock and Roll!
- How old are those participants now??????
Intimacy

- Sharing and closeness between partners
- Encompasses touch and communication
- Emotional and social interaction, linked with overall sense of wellness, happiness

Hardem, Cancer Nursing, 2008. 31(2):9-17
Sexuality

- Central aspect of being human throughout life, encompasses sex, gender identity, orientation, eroticism, pleasure, intimacy and reproduction
- Experienced in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles, and relationships... Sexuality is influenced by interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

http://www.who.int/reproductive-health/gender/glossary.html
Palliative Care

- Approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

http://www.who.int/cancer/palliative/definition/en
Palliative Care

- Provides relief from pain and other symptoms
- Affirms life, regards dying as normal process
- Intends neither to hasten nor postpone death
- Offers support to help patients live as actively as possible until death
- Support system to help family
- Team approach to address needs of patients/families
- Applicable early in course of illness

http://www.who.int/cancer/palliative/definition/en
Barriers to providing optimum QOL

US!!!!!!!
Barriers to providing optimum QOL

- Assessment
- Physical limitations
- Environmental constraints
- Spiritual/psychological issues
- Families
Barriers to Exploring Sexuality

- Not considering patients as sexual beings
- Felt vulnerable discussing sensitive topic
- Displayed a fear of being misinterpreted by their clients and colleagues when they initiate a discussion on sexuality
- Avoided the topic
- Employed a medicalized approach to all forms of communication
- Held unchecked assumptions about patient intimacy and sexual needs based on patient’s age, diagnosis, disease status, culture and partnership status

Hordern AJ, Street AF. Soc Sci Med. 2007;64(8)
Patients vs Healthcare Professionals

- Patients value sexuality and want to discuss it with doctors
- Patients: “translate” information about side effects of treatments into the meaning they have in real life
- Patients: “person to person” approach, tailored to them
- Patients: don’t just hand out leaflets
- Patients: don’t automatically “medicalize” the solution (i.e. offer a pill)

Healthcare Professionals vs Patients

- Physician/HCP: no training/expertise in this
- Physicians/nurses: patients rarely refuse to discuss, some state it no longer applies. No one offended.
- The two are “worlds apart”
- Physicians are “science based”, linear, “objective”
- Patients and families are “lived experience”, associative, circular

Solution: person-oriented approach

Sexual Dysfunction: We Have A Role

- About 50% of prostate cancer patients and breast cancer patients report severe levels of sexual dysfunction:
  - Physical symptoms
  - Emotional symptoms
  - Interpersonal challenges
- Assessment is not routinely done by providers
  - No standardized sexuality questionnaires
  - Mismatched priorities
  - Providers unfamiliar with workup, underlying factors such as medications, treatments

Fast Facts #293 August 2015 JPM
Sexual Dysfunction: We Have A Role

- We are missing distress and quality-of-life issues

Recommendation:
- Ask the (open-ended) question!!!!

Fast Facts #293 August 2015 JPM
Assessment tools

- PLISSIT
  - ExPLISSIT
- ALARM
- BETTER
- PLEASURE
- EORTC QLQ-cancer specific modules
- Other HR QOL scales specific to disease, eg prostate ca, gyn ca.....FACT and FACIT
- SF-36 modifications
PLISSIT/ExPLISSIT

- **P**=permission to have sexual feelings
- **LI**=limited information about tx/dz/disability
- **SS**=Specific Suggestions
- **IT**=Intensive Therapy

- **P**=identification of current, potential issues
- **LI**=correct misconceptions, provide accurate info
- **SS**=addresses all aspects of sexuality
- **IT**=identify services/refer

BETTER

- Bring up issues of sexuality/function
- Explain that sexuality integral to QOL
- Tell patients about resources/refer
- Timing is crucial; discussions at patient/partner’s pace
- Education pt/partner about expected/potential alterations sexual function
- Record discussion, assessments, interventions, outcomes

PLEASURE

- Partner
- Lovemaking
- Emotions
- Attitudes
- Symptoms
- Understanding
- Reproduction
- Energy

Krebs L. Seminars in Onco Nursing 2008. 24 (2):80-90
Open Ended Questions

- How, if at all, has your illness/treatment changed the way you feel about yourself as a man/woman?
- Can you tell me how your illness/treatment has altered the way you feel about yourself as a husband/wife/partner?
- Can you help me understand how the diagnosis of cancer (illness) has affected your relationship (be it physical/sexual/emotional) with your husband/wife/partner?
Barriers to providing optimum QOL

- Assessment
- **Physical limitations**
- Environmental constraints
- Spiritual/psychological issues
- Families……
Physical Limitations

- Palliative Performance Scale=?????
  - (Karnovsky Performance Scale)
- Comorbid diseases: Heart disease, cancer, arthritis, chronic obstructive pulmonary disease, dementia, anemia, uremia, fatigue
- Side effects of medications
- Stigmata of disease: tumors, wounds, odors
- Stigmata of treatment: surgery, radiation therapy, chemotherapy
- What do you do with the ostomies and tubes?
Medications that impact Sexual Function

- Antidepressants
  - SSRI, SNRI
  - TCAs, MAOIs
- Antipsychotics
- Anxiolytics
- Anticonvulsants
- Diuretics
- Alpha blockers
- Beta blockers

- Lipid lowering agents
- Digoxin
- Opiates
- Hormones
- Steroids
- H2 receptor blockers
My Heart Tie "Original" Ostomy Pouch Covers

If you wear a Two Piece Pouching System, you may want to choose our "Original" My Heart Tie Ostomy Pouch Cover. This cover works by using a drawstring at the back of the heart tie.

My Heart Tie "New One Piece" Ostomy Pouch Covers

If you wear a One Piece Pouching System, you will want to choose our "New" One Piece My Heart Ties Ostomy Pouch Cover. This cover works by using a double-sided tape system created by our friends at Hollywood Fashion Tape™.

Which one is right for you?
Help me choose.
Physical Limitations in Elderly

- Normal versus “not normal” aging of sexual organs
- Vaginal dryness and atrophy
- Erectile dysfunction (hypertension, vascular disease, diabetes mellitus, EtOH)
- Deconditioning
Symptoms common to chronically ill patients

- Shortness of breath
- Pain
- Fatigue
- Nausea/vomiting
- Dry mouth
Barriers to providing optimum QOL

- Assessment
- Physical limitations
- **Environmental constraints**
- Spiritual/psychological issues
- Families......
Environmental Constraints

- Significant number of elderly living in communal/institutional settings
- ~ 900K to 1M people live in 36,000 ALFs nationwide (2008)
- 3.2 M residents of NHs during 2008 (1.74M beds)
Environmental Constraints

- Multigenerational homes
- 2010 census 5.6% US households multigenerational
- Hawaii: 11.1%, Mississippi 7.3%
- 4.3 M adults have parents move in
- Higher among immigrant populations

What is the biggest issue here? *privacy*
Barriers to providing optimum QOL

- Assessment
- Physical limitations
- Environmental constraints
- Spiritual/psychological issues
- Families…….
PsychoSocial issues

- Body integrity
- Self Image
- Need for touch/ holding tight while letting go
- Disfigurement is isolating/ rejection
- “I can’t be the man”
- Roles shift-->Caregiver becomes strong
- Urinary/fecal incontinence + fear of offense
Spiritual issues

- Spirituality: that which gives us breath
- The human “matrix”
- Existential issues
  - Why me?
  - Why am I so disfigured?/Disabled?/Unlovable?
  - Where is God?
Loss of Something Precious:
The Broken Butterfly
Barriers to providing optimum QOL

- Assessment
- Physical limitations
- Environmental constraints
- Spiritual/psychological issues
- Families
Families

- “They want to do WHAT??????”
- “She’s too sick for that.”
- “I can’t leave them alone…What if something happens?”
- “Will this hurt him? I don’t want him to die because he had sex.”
- Issues of consent in facilities—mental model of parent having sex
Treatment

Medical

Versus

Adaptive/supportive strategies
Medical/Treatment interventions

- Streamlining medications!!!!!
- Vaginal Dryness: KY or Astroglide
- Vaginal dilators
- Erectile dysfunction: look for underlying causes or medications
  - PDE-5 Inhibitors
    - Cost
    - Efficacy
    - Combination therapy
    - Absolute contraindications
- Vacuum devices
- Penile injections/urethral suppositories
- Implants
Medical/Treatment interventions

- Odors: topical or oral antibiotics, antifungals
- Radiation/chemotherapy to treat tumors
- Anti-anxiety agents
- Antidepressants
- Hormone tx if not hormone-sensitive cancer
  - Contraindicated in breast, uterine, prostate
- Antisecretory agents for oral secretions
Adaptive strategies/counseling

- Disguising “deformity” during intimate moments: teddies, ostomy covers, muscle shirts
- Wigs, prostheses, plastic procedures
- Energy conservation/ choosing the “right time”
- Alternative methods of intimacy, stimulation, positions and bracing
- Counseling/therapy (NASW/AASECT)
- Journalaling
Providing supportive environment for intimacy

- Creating “space” or “time”
- Counseling for patient and loved one, family
- Strategies for loved one to participate
- Acknowledging importance of intimacy for patient and loved one

- Which team members can do this?
Special Populations

- Cardiac
- Cancer
- Elderly
- Gay/Lesbian
- Others
Sexual Activity and Cardiac Disease

- Decreased sexual activity common in CVD patients related to anxiety and depression.
- Sexual activity is 3-5 METS (MET = climbing 2 flights of stairs or brisk walk)
- Coital angina <5% all anginal attacks.
- Sex and sudden death: in 5559 cases of sudden death: 34 (0.6%) during sex.
- Rates are 0.6-1.7% death during coitus

*Circulation* February 28, 2012
Cancer

- Tremendous number of resources
- Primary issue for cancer patients:
  1. Survival
  2. Treatment (consequences)
  3. Trust in healthcare team
  4. Intimacy/sexuality
Cancer

Sexuality impacted by:

- Involvement of sex organs, directly or indirectly
- Ca prostate, gyn cancer, breast cancer
- Colon or pelvic malignancies
- Head and neck cancer
- Nerve pain, cancer syndromes, amputations, paralysis
Elderly

- The elderly are NOT “asexual”
- Study: “young old (57-64)” 73% active
  - “middle old (65-74)” 53% active
  - “old (75-85)” 26% active
  - Over 85............
- Complex interplay of aging, culture, comorbid conditions, medications
- Divorce, family disruption, widow-hood create loneliness
- Environment

Elderly--Cognitive Dysfunction

- Most literature is about “sexually inappropriate behavior”
- Survey 144 American NH re: prevalence of sexual activity in dementia population: 16% men, 10% women
  - <5% “genital”
- **Capacity? Is this consensual?**
- Public displays/redirection of behavior
- Staff training
- Family involvement & counseling

Kuhn D. Alz Care Quarterly 2002; 3(2): 165-176
Gay/Lesbians

- Symptoms are the same!
- Treatments are the same!
- Intimacy:
  - Sharing and closeness between partners
  - Encompasses touch and communication
  - Emotional and social interaction, linked with overall sense of wellness, happiness

- Stan and Jim..............

- Don’t forget Power of Attorney for Healthcare and impact of family at end of life for unmarried same sex couples
Next Steps

- Recognize intimacy as element of QOL
- Measures for assessment
- Holistic interdisciplinary approach
- Resources in various medical populations: disabled, ostomy, cancer, elderly, gay/lesbian
- Cultural sensitivity
- Engage bereavement services early
Why Bereavement?
Adding Intimacy to Vital Signs

- Blood Pressure
- Pulse
- Respirations
- Temperature
- Pain
- Suffering
- Bowel status
- Urinary incontinence
- Functional status
- Intimacy and sexuality
Questions?

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