Intimacy at End of Life:  
A Conversation Worth Having with Terminal Patients and Caregivers  

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Purpose

♥ Explore and understand intimacy at end of life  
♥ Broaden the definitions of intimacy  
♥ Increase comfort in addressing intimacy-related topics with patients and caregivers
Intimacy Defined

A close, familiar, and usually affectionate or loving personal relationship with another person or group.

Importance at EOL

♥ Improves quality of life
♥ Aligns with holistic care
♥ Improves the dying experience
♥ Allows for existential problem solving
TYPES OF INTIMACY

SOCIAL

INTELLECTUAL

SPIRITUAL

EXPERIENTIAL

EMOTIONAL

SEXUAL

Potential Barriers to Intimacy at End of Life
Importance of Intimacy: Patient Experience

Impact at End of Life

- Reduction in anxiety
  - What will happened to my loved ones?
  - What will dying look like?
- Improvement of perceived self-worth
- Explore/address Existential issues
Importance of Intimacy: Caregiver Experience

Intimacy and Relationship Type

♥ Level of Intimacy depends on Relationship Type:
  - Strengthening
  - Reconstruction
  - Intimacy Maintained
  - Estrangement Maintained

♥ Influenced by relationship prior to diagnosis and reaction to illness
Strengthening

♥ Become more affectionate with overcompensation
♥ Limit caregiver activity
♥ Enthusiasm for meeting patient demands
♥ Tendency to self-sacrifice
♥ Conceal own emotions

Reconstruction

“"I juggled caregiving responsibilities and my mother’s demands while managing to maintain my life outside of caregiving.”
- 40’s daughter

♥ Provide care without yielding to patient demands
♥ Respect for patient's intentions
Intimacy Maintained

♥ Maintain intimate relationship present before diagnosis
♥ Lack of change in relationship despite impending death
♥ Faithful care with lack of deepening sympathy

Estrangement Maintained

♥ Fail to establish a good relationship before or during patient care
♥ Indifference towards patient
♥ Denial of patient’s imminent death

“Because there were no other caregivers, that was my role.”
- 40’s nephew
Societal Attitudes About Sexuality at End of Life

♥ Sexuality is taboo
♥ Sexuality defined by youth and reproduction
♥ Older people are not interested in sex
♥ “Cougars” and “Dirty Old Men”
Is Sexuality Important to a Dying Person?

- 0%/100%
- Follows Lifelong Pattern of Function
- Affirms living
- Expresses love and affection
- Provides Escape
- Relieves Tension

Factors Affecting Sexuality at End of Life

- Psychosocial Issues
- Physical factors/side effects
- Caregiver Factors
- Healthcare Provider Factors
Professionals’ Attitudes Regarding Intimacy-Related Conversations with Patients

Importance of Conversations

Research overwhelmingly indicates patients would like to have conversations with their healthcare providers about sexual/intimacy related topics.

Research indicates patients at end-of-life are rarely, if ever, asked about sexual health.
Matzo & Hijjazi

♥ 0% of patient participants were asked about sexual/intimacy needs
♥ 100% of patient participants stated lack of communication with HCP
♥ 75% of nurse participants rarely or never ask their patients about intimacy or sexual health

Why Conversations are Not Happening

♥ Lack of Assessment due to:
  – Sensitivity of Subject
  – Topic Lacks Priority
  – Patient Characteristics
  – Not enough education
Intimacy Education

- Patients and Caregivers
- Importance of intimacy at end-of-life
- Educate on alternate types of intimacy
- Suggest ways to build alternate types of intimacy
Sexual Intimacy and Alzheimer’s Disease and Related Disorders (ADRDs)

Alzheimer’s Disease and Related Disorders (ADRDs)
♥ Characterized by loss of intellectual functioning
♥ Onset can alter perception of self, others, and situations
♥ Impacts ability to exchange thoughts and feelings (intellectual intimacy)
♥ Impacts ability to engage in activities to support one another (experiential intimacy)
Differences in Gender of Caregivers

ADRD Patients Continuing Sexual Relationships

- Large division of opinions
- Ability to consent/Mental capacity
- Verbal consent versus showing interest
- How is “interest” defined?
- Protection vs. Autonomy
Mental Capacity Defined

- Understands information given
- Retains information long enough to make decision
- Weighs information available to make decision
- Communicates decision – by any means
  - Talking
  - Sign Language
  - Simple muscle movements (blink eyes, squeeze hand, etc.)

Case Study
Group Discussion

- Boomer Sex With Dementia Foreshadowed in Nursing Home
- Sex in Geriatrics Sets Hebrew Home Apart in Elderly Care
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References


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