Sexuality in Long–Term Care

Open Your Mind (And Close the Door, Please)

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Objectives

• Discuss prevailing perceptions about sexuality and older adults as well as the capacity of elders with dementia to consent to sexual activity
• Examine the challenges faced by long–term care providers in facilitating safe sexual expression among residents and for managing inappropriate sexual expression
• Consider ways to preserve residents’ rights to intimacy and sexuality while complying with regulatory requirements
Introduction

Definitions

• Sexuality
  o A part of personality that encompasses sexual beliefs, attitudes, values, behavior, and knowledge

• Intimacy
  o Interpersonal relationship between two people who may or may not be engaging in sexual activity
Definitions

• Sexual expression
  o Kissing, fondling, masturbation, oral sex, intercourse, touching, hugging

• Expressions
  o Sending flowers, providing comfort and warmth, dressing up, expressing joy, maintaining beauty and physical experience, flirtation, affection, passing compliments, proximity and physical contact

Domains of Sexuality

- Biological
- Psychological
- Cultural
By the Numbers …

• 45% of older men and 8% of older women think of sex at least once a day (Fisher, 2010)
• 28% of men aged 66–71 living in the community report having intercourse at least once a week (Marsiglio & Donnelly, 1991)
• 60% of men and 43% of women ages 80–91 remain sexually active (Starr & Weiner, 1981)

Physical Changes in Women

• Lower libido or slowing of sexual arousal
• Hot flashes and/or night sweats
• Sleep disturbances
• Emotional changes
• Vaginal dryness and itching
• Increased sensitivity to sounds
• Dry skin
• Weight gain and/or food cravings
Physical Changes in Men

• Longer time to obtain erection
• Inability to maintain erection
• Increased time between erections

Sexuality in Long–Term Care

• 25% of people living in SNF say they are lonely
• 40% saying they are sometimes lonely
  ○ A major fear is that they’ll die alone
Consider Their History …

- Grew up at a time when sexual behavior was never discussed
- Sexual activity was suppressed
- Education was minimal
- Modesty was an important value
- Gender differences exist

Obstacles to Sex in Residential Facilities

- Lack of privacy
- Negative attitudes toward alternative lifestyles
- Lack of education of staff
- Lack of education of adult children
- Physical and mental limitations
- No federal regulations that specifically address sexual activity in nursing homes
Strategies to Address Needs

- **Touch**
  - For example, hair grooming, hand massage, manicure or pedicure, ROM exercises, back rub, taking pulse

- **Consistent staffing**

- **Counseling and Education**

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Staff Attitudes About Resident Sexuality
The “ICK” Response

Sexual Expression in LTC

- Love and caring
- Romance
- Eroticism
Staff Responses to Sexuality

- Standing guard
- Reactive protection
- Guarding the guards
- Proactive protection

Inappropriate Responses

• Placing notes on the medical record
• Reporting sexuality at meetings
• Snickering or giggling
• Discussing sexuality with colleagues
• Reprimanding or otherwise scolding
• Praying over the person
• Invasion of privacy

SAID Survey (Kuhn, 2002)

• Competent and consenting residents who are single are entitled to be sexually intimate
• Competent and consenting residents who are married, but not to each other, are entitled to be sexually intimate with one another in a care facility
• Residents with dementia are not capable of making sound decisions regarding sexual relationships
• A spouse living in the community is entitled to become intimately involved with someone else if the spouse has dementia and lives in LTC
• A resident with dementia is entitled to be sexually intimate with two different residents as long as there is no sign of coercion in these relationships
SAID Survey (Kuhn, 2002)

- A resident is entitled to masturbate in private as long as his or her personal safety is ensured
- Two residents of the same sex are entitled to be sexually intimate as long as it is consensual
- If family members object to a relative with dementia having sexual relations with others, it is the duty of the staff to prevent such activity
- A resident displaying hypersexual behavior should be transferred out of the facility
- No one should interfere in the sexual lives of residents as long as no laws are broken

Training Programs

- Uncover staff bias, morals, thoughts
  - Staff can direct the training and individualize it to their population
- Debunk myths about older sexuality
  - Helps caregivers recognize that sexuality is a human need that does not disappear with age
Staff Training Program Elements

- Resources
- Education
- Support
- Protection
- Empowerment
- Confidentiality
- Tactfulness

(Lorenz, 2009)

Family Influences on Resident Sexuality
Reactions of Family Members

• Supportive
• Angry
• Indifferent
• Unsupportive
• Humiliated
• Embarrassed

Spousal Issues

• How am I obliged as a spouse or partner to someone who no longer recognizes me?
• How do I maintain a sexual or intimate relationship when my feeling toward my spouse have changed?
• How to I handle my feelings of anger, frustration, and entrapment?
• How do I cope with my spouse’s changes in sexuality? (e.g., hypersexual, accusations of unfaithfulness, suspicion)
• How can I meet my spouse’s needs? I love my spouse, but I cannot bring myself to be intimate.
Adult Children

- Feel the need to make decisions including separation
- Many not be aware of parent’s sexual behavior
- Does the facility need to tell them EVERYTHING?

In most cases, the facility will choose the direction of the family members over the wishes of the resident
Consider ...

A “sexual power of attorney” because without one, the adult children will feel free to control the intimacy of loved ones.
Ways Dementia Affects Sexuality

- Early stages: interest in sex, but performance issues
- Partner with AD may have interest and capability; way to retain one normal area of a relationship
- Partner with AD is hypersexual
- Person with AD has no interest or thinks sexual activity is unacceptable

Spouse/Partner Issues

- Female caregivers uncomfortable with partner’s increased sex interest; males do not experience the same (Duffy, 1995)
- With loss of communication ability comes loss of reciprocal feelings
- Spouse may feel alienated and withdraw affection that was once important to both partners
The Move to LTC

• Affection often increases when the spouse with AD is moved into LTC
• Nursing homes can be places of isolation and loss
• Physical contact from others and intimate relationships can be calming and reassuring

The Question of Consent

• MMSE score 14+ has been used as the cut off for consent to sexual activity
• MMSE does not address emotional state

Is the MMSE enough?
Is Assessment Enough?

- Observation
- Interviews with staff, family
- Involve other professionals
- Team meeting to discuss findings

Interview for Consent  (Lyden, 2007)

- Interviewer should have good and comfortable relationship with client
- Utilize someone familiar to assist if impaired speech or translator needed
- Explain the reason behind the meeting
- Assess rationality, knowledge, voluntary agreement
Criteria for Sexual Capacity

- Voluntariness
- Safety
- No exploitation
- No abuse
- Ability to say “no”
- Socially appropriate time and place

Determining Functional Competence

- Determine whether the resident has the ability to express his or her desires
- Determine what critical interests or values might be affected by acting upon the desires
- Determine if the resident can consider these interests when making a decision
- If not, then the nursing home needs to consider or decide whether the value of the intimate relationship outweighs the value of the critical interest affected
For What?

Capacity/competence can only be assessed in relation to a specific demand or task

Keep in Mind

• Cognitive memory may be impaired, often times emotional memory is not
  o Cognitive impairment does not erase the need for affection or intimacy
• If a person can consent to one relationship, that doesn’t mean they can consent to another
  o Each relationship must be approached differently
Dilemma of Adultery

Is the nursing home’s obligation to the resident or to his/her spouse?

Do we hold a person with dementia at a higher standard than everyone else?

System Bias?

• System bias relies on the opinion of the non–resident spouse, not the resident (Tenenbaum, 2009)
• Our responsibility should be to the resident
  o Should we end an intimate relationship based solely on the request of a non–resident spouse?
Helping to Decide

- Substituted judgement
- Best interest
- Functional competence
- Authentic self

What Can We Do?

- Include sexual history in admission records
  - For example, orientation, sleeping arrangements at home, level of sexual interest, capacity
- Facility should have a consent policy; all staff must be trained to follow it
Assumptions to Follow (Ballard, 1995)

• Individuals with AD may behave in childish ways, but must be treated as an adult
• People with AD are still sexual and may express a variety of sexual behaviors
• You cannot force someone with AD to remember
• Behaviors are not always as they seem

Inappropriate Behaviors
Definitions

• **Disinhibition**
  o Lack of restraint; disregard for social conventions

• **Hypersexuality**
  o Abnormally high desire to engage in sexual activities
Inappropriate Behaviors

- Fondling, hugging, kissing strangers
- Masturbating in public
- Undressing in public
- Using sexual language
- Sexually suggestive activity
- Initiating sexual activity
- Aggressive sexual overtures
- Exposing oneself
- Urinating in public
- Requesting excessive genital care
- False accusation of sexual abuse

Gender Differences

- Men like to touch and women like to be touched (Mayers, 1998)
- Women want comfort/affection; men are more aggressive/forceful (Nay, 1992)
- More inappropriate sexual behaviors from men than women (Archibald, 1998)
Categories of Sexual Expression

• Intimacy seeking behaviors

• Disinhibited behaviors

• Nonsexual behaviors

Consider This …

• Is the behavior related to past abuse?
• What are the biases and beliefs of the person reporting the behavior?
• What is the sexual history of the resident?
• Is the person compensating for loss?
• Is this a case of misunderstanding/misinterpretation?
Assessing Behaviors (Ballard, 1995)

• Exactly what is the resident doing?
• A pattern? Happening frequently?
• Is the behavior sexual? Or does it have another cause?
• A triggering incident?
• Changes to the environment?
• Has medical condition changed? New medication added?

Assessing Behaviors (Ballard, 1995)

• Forgotten social rules?
• Need for attention?
• Why is this behavior a problem?
• For whom is it a problem?
• Risk/benefit analysis?
• Psychological need?
• Caregiver misinterpretation?
Behavior Log

• What activity was going on right before this incident occurred?
• What happened right before the behavior?
• What was the behavior?
• What action did staff take regarding the behavior?
• Was action / intervention effective?

How to Respond (Stimson, 2012)

• Remain calm
• Be respectful
• Reassure others the patient means no harm
• Show no awareness
• If in a common area, lead resident away
• Step away from the situation
• Do not reprimand, scold or yell
Pragmatic Tips

• Approach the resident as an adult
• Modify the environment to encourage desired behaviors
• Staff assess their own beliefs/biases
• Chart and evaluate behaviors objectively
• Inform family when behaviors have legal, ethical, or social consequences
• Ensure families know sexual history will be assessed

Interventions

• Behavioral treatments
  o E.g., restrictive clothing
• Medications
• Person-centered routine
Keep in Mind ...

- Sex offenders may be your residents
- History of sexual abuse
- Ensure any relationship is consensual

Lesbian, Gay, Bisexual, and Transgendered Residents
Statistics

- 73% of gay and lesbian survey respondents said that discrimination occurred in retirement communities
- Greater than 1/3 said they would go back into the closet if they were forced to move into one

(Johnson, Jackson, Arnette, & Koffman, 2005)

Fears of Moving to LTC

- Fear of caregiver neglect or rejection
- Fear of not being accepted by other residents
- Concern about offending others
- Preference for gay-friendly residential options in LTC

(Stein, Beckerman, & Sherman, 2010)
Family Circle

• Delay in moving into LTC
  o Family members care for them longer at home
• Family members may not be true family members
  o Circle of friends

What Can We Do?

• Intake/Admissions
  o Most nursing homes do not ask about sexual orientation (Doll, Bolender, & Hoffman, 2011)
  o Revise forms to read domestic partner or same-sex partner
  o Clearly indicate confidentiality
What Can We Do?

• Staff attitudes
  o Don’t assume resident is heterosexual
  o Treat residents with respect and dignity
  o Anti–discrimination policies that specify sexual orientation and gender identity
  o Staff response

What Can We Do?

• Environment and marketing
  o Pictures in common areas
  o Reading material in the library?
  o Pamphlets, posters, websites, brochures, resident rights policies contain inclusionary language
Health and Sexuality

Diseases Affecting Sexuality

- Diabetes
- Hypertension
- Heart disease
- Incontinence
- Kidney disease
- Stroke
- Neurological disorders
- Cognitive disorders
PLISSIT (Wallace, 2008)

• Permission
• Limited Information
• Specific Suggestions
• Intensive Therapy

Risk of HIV and STDs

• Many have had only one partner
• Less likely to know risks of contracting HIV
• Many do not use protection
  o 60% of unmarried women 58–93 said they had not used any sort of protection

(Lindau, Leitsch, Lundberg, & Jerome, 2006)
Reasons for STDs  (Resnick, 2003)

- Women cannot get pregnant; do not choose to use protection
- Rate of STDs is 2X as high in older men using medications for ED
- Better health, sexually active longer
- Older adults have ignored safe sexual practices

Reasons for STDs  (Resnick, 2003)

- Older adults raised when men made the decisions
  - A man does not wear a condom if he chooses not to
- Men have many options for sexual partners
- Internet dating sites
- Men are ignoring safe sex practices
Environment

Hindrances to Privacy

- Unlocked door policies
- Evening bed checks
- Roommates
- Staff access to health-related information
  - Private rooms do not always guarantee privacy
    (Calkins & Cassella, 2007)
What Can We Do?

- Wait for permission to enter a room
- Discuss sensitive information when others are not present
- Cordon off a “visiting room” for overnight guests

No Spare Room?

- Schedule visits when roommate is out
- Help couple make arrangements at a local hotel
- Make an unoccupied room available
- Find ways to make resident rooms more private
- Add locks on the inside of the room
- Accommodate family caregivers
Policy

For Whom is the Policy?

• It appears as though LTC facilities make decisions based upon the wishes of the family instead of the resident
• Adult children are primary consumers of LTC services and thus need to be catered to
Key Stakeholders

- Dietician
- Housekeeping
- Nursing
- Social service
- Activities
- Therapy
- Physician
- Family
- Administrator
- Board members
- Pastoral care
- Volunteers
- Ethics professionals
- Residents
- Ombudsman

Developing a Policy

- Determine the culture of the facility
  - What is normal and acceptable?
  - What is inappropriate or pathological?
- Review policies from other organizations
- Policies will also differ by level of care
Policy Elements

• Admissions
  o Gather information re: sexual history, interest, activity

• Working definitions
  o E.g., sexuality, intimacy, sexual behavior
  o What is considered normal and acceptable?
  o How will you determine consent?

Policy Elements

• Consent
  o Expression allowed with consent and benefits outweigh risks
  o Care staff may decide whether to permit sexual behavior/activity
  o Staff determine and document consent
  o With family objection, facility seeks a mutually agreeable solution
Policy Elements

• Risk
  o Assess for resident’s ability to understand risks/consequences of an intimate relationship
  o Harm or offense
    • Interference from staff should only occur if there is significant harm or offense to others AND
    • If harm is greater than benefits

Policy Elements

• Shared rooms
• Staff training
• Reporting procedure
• Appropriate staff interventions/responses
• Sexual ethics committee
• Police involvement
• Resident sexual education and support
• Case studies
Role of Ombudsman (Cornelison & Doll, 2012)

- Risk associated with dementing illness
- Risk
- Knowledge
- Values
- Privacy

Successful Policy (Ballard, 1996)

Reviewed at least every 2 years

- Holistic approach considering social, emotional, spiritual, physical, sexual needs
- Staff feel comfortable addressing intimacy and sexuality
- Guidelines for resolving dilemmas
- Families understand potential for intimate relationships and facility policies
More Questions Than Answers