Sexuality in Long-Term Care

Open Your Mind (And Close the Door, Please)

Kathleen Weissberg, OTD, OTR/L
Education Director -- Select Rehabilitation
kweissberg@selectrehab.com

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

Definitions

• Sexuality
  • A part of personality that encompasses sexual beliefs, attitudes, values, behavior, and knowledge
• Intimacy
  • Interpersonal relationship between two people who may or may not be engaging in sexual activity

Definitions

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

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**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

**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
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)
FTag 175

The resident has the right to share a room with his or her spouse when married residents live in the same facility and both spouses consent to the arrangement.

FTag 164

- The resident has the right to personal privacy and confidentiality of his or her personal and clinical records.
  - Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups, but this does not require the facility to provide a private room for each resident.

Ftag 241

The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.

FTag 460

Be designed or equipped to assure full visual privacy for each resident.
FTag 242

• Self-Determination and Participation
  o The resident has the right to make choices about aspects of his or her life in the facility that are significant to the resident

FTag 246

• Accommodation of Needs
  o A resident has the right to reside and receive services in the facility with reasonable accommodation of individual needs and preferences, except when the health or safety of the individual or other residents would be endangered

FTag 223

• The resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.

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 do 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?

Consider …

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

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?
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
  o 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

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?
<table>
<thead>
<tr>
<th><strong>Assessing Behaviors</strong> (Ballard, 1995)</th>
<th><strong>Behavior Log</strong></th>
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</thead>
<tbody>
<tr>
<td>• Forgotten social rules?</td>
<td>• What activity was going on right before this incident occurred?</td>
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<tr>
<td>• Need for attention?</td>
<td>• What happened right before the behavior?</td>
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<tr>
<td>• Why is this behavior a problem?</td>
<td>• What was the behavior?</td>
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<td>• For whom is it a problem?</td>
<td>• What action did staff take regarding the behavior?</td>
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<tr>
<td>• Risk/benefit analysis?</td>
<td>• Was action / intervention effective?</td>
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<td>• Psychological need?</td>
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<tr>
<td>• Caregiver misinterpretation?</td>
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<th><strong>How to Respond</strong> (Stimson, 2012)</th>
<th><strong>Pragmatic Tips</strong></th>
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<td>• Remain calm</td>
<td>• Approach the resident as an adult</td>
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<tr>
<td>• Be respectful</td>
<td>• Modify the environment to encourage desired behaviors</td>
</tr>
<tr>
<td>• Reassure others the patient means no harm</td>
<td>• Staff assess their own beliefs/biases</td>
</tr>
<tr>
<td>• Show no awareness</td>
<td>• Chart and evaluate behaviors objectively</td>
</tr>
<tr>
<td>• If in a common area, lead resident away</td>
<td>• Inform family when behaviors have legal, ethical, or social consequences</td>
</tr>
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<td>• Step away from the situation</td>
<td>• Ensure families know sexual history will be assessed</td>
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<td>• Do not reprimand, scold or yell</td>
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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

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
  - Family members care for them longer at home
- Family members may not be true family members
  - Circle of friends

What Can We Do?

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

What Can We Do?

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

What Can We Do?

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

Diseases Affecting Sexuality

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

• Permission
  o Give clients permission to speak about sexual concerns
  o Validates as a legitimate health concern
  o Ask if it is okay if you ask questions
  o Develop an environment of openness and comfort

PLISSIT (Wallace, 2008)

• Limited Information
  o Informative, educational approach
  o Patients may be given books, magazines, videos, etc. to provide relevant and accurate information

PLISSIT (Wallace, 2008)

• Specific Suggestions
  o Provide tips, directions, exercises used to treat sexual problems
  o Tailored to meet specific needs of each case
  o Sexual history of client/partner is obtained

PLISSIT (Wallace, 2008)

• Intensive Therapy
  o Which cases are resulting from additional underlying causes?
  o Is a referral to a medical professional needed?
**Risk of HIV and STDs**

- Many have had only one partner
- Less likely to know risks of contracting HIV
- Many do not use protection
  - 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

**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  
  o What is normal and acceptable?  
  o 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
  - Assess for resident’s ability to understand risks/consequences of an intimate relationship
  - 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

- Shared rooms
- Staff training
- Reporting procedure
- Appropriate staff interventions/responses
- Sexual ethics committee
- Police involvement
- Resident sexual education and support
- Case studies

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