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# Sexual Expression and Physical Intimacy in the Dementia Context: Balancing the Risks with Human Rights

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Everyone Makes a Mark

# Objectives

1. Review classification of sexual behavior in the dementia context.
2. Discuss assessment approaches to sexual behavior.
3. Discuss interventions to manage sexual behavior in the context of clinical and legal obligations.

# Sexuality: Elements of the Definition

- Value laden
- Need for touch, intimacy
- Feelings about oneself, one's body
- Need for intimate connections
- Sexual behaviors
- Desire
- Comfort
- Well-being



# Principles

1. In order to deal effectively with human sexuality, the health care professional must first accept her/his own sexuality
2. The primary need is to deal comfortably with one's own feelings about sexuality so that as a care giver one can deal more effectively with patient's sexual feelings
3. Human sexuality must also be integrated as a significant component into the care giver's concept of overall health

# Values/Beliefs/Attitudes

## – A Declaration

1. Sexuality is a basic need in human experience.
2. Sexual expression is a component of health.
3. Expression of sexuality is a human right.
4. Decline in sexual activity as one ages may be less than expected.
5. Older people, including those with cognitive impairment, continue to have sexual feelings.
6. Older people, including those with cognitive impairment are capable of normal sexual activity.

(de Medeiros et al, 2008; Heath, 2011; Robinson, 2003)

# Sexual Patterns in Dementia

- The partner with dementia has no sexual interest
- The partner with dementia is sexually interested but has difficulty with performance
- The partner with dementia is sexually interested and capable
- The partner with dementia is hypersexual
- The partner with dementia has sexual preferences/interests that have been suppressed throughout life

# Classification of Sexual Behaviour in the Dementia Context

## Types

1. Retained sexual intimacy (RSI) – appropriate sexual behaviours that occur in the wrong place.
2. Hypersexuality – inappropriate sexual behaviours; not a form of sexual behaviour retained in AD.

(Robinson, 2003)

# Retained Sexual Intimacy (RSI)

## Examples

1. Removing one's clothing.
  2. Masturbation.
  3. Courting behavior.
  4. Sexual talk/repartee/flirting.
  5. Touching, caressing, kissing.
- (Robinson, 2003; Sloane, 1995)

# The Behavior that Concerns us the Most: Hypersexuality

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## Types

1. Persistent, uninhibited sexual behavior directed at oneself or others;
2. Inappropriate behavior in relation to others.

## Examples

1. **Compulsive** masturbation – public or private.
2. Pattern of lewd, suggestive language.
3. **Unwanted, uninvited fondling** of personal body parts of **others**.
4. **Fondling** of personal body parts of **caregivers**.
5. Flirtation.
6. **Disrobing of self or others**.
7. **Overt sexual acts. (?)**

(Kuhn, Griener, Arseneau, 1998; Robinson, 2003)

# Alternative Viewpoints – Retrospective case-control study N = 165 elders with dementia living in a care facility

## Three types of behavior evident

### 1. Intimacy-seeking – (associated with AD, moderate – severe)

1. Misdirection of affection or courtship

### 2. Disinhibited – (associated with non-AD, mild)

1. Impulsive
2. Indiscriminate
3. Invasive, intrusive
4. Opportunistic

### 3. Nonsexual –

1. Disrobing because of soiled clothing
2. Climbing into another resident's bed

(de Medeiros, Rosenberg, Baker, Onyike, 2008)

*“First evidence that the form of improper sexual behavior may differ according to type of dementia.” (p. 376)*

# Prevalence/Incidence of Hypersexuality in the Dementia Context

1. 7% of 178 community dwelling elders with dementia (Burns, Jacoby & Levy, 1990).
2. 4% of 124 nursing home residents with dementia (Ryden, Bossenmaier & McLachlan, 1991).
3. 5% of 614 nursing home resident with dementia (Wagner, Teri & Orr-Rainey, 1995).
4. > number of males (Robinson, 2005).

# Hypersexuality in the Dementia Context

## Key Features

1. Directed at a number of people, NOT one particular relationship - **indiscriminate**.

## Inherent Risks

1. Compounds social isolation of family caregivers and PWD.
2. Reduces receptivity to home care and transfer to LTC.
3. Increases likelihood of labeling and stigmatization.

(Robinson, 2003; Miles & Parker, 1999)

# Possible Causes of Hypersexuality

## Causes

1. Injuries to temporal/frontal lobe of the brain.
2. Disruption in neural pathways related to sex drive.
3. Inappropriately expressed psychological need for intimacy.
4. Lack of touching and intimacy.
5. Forgetfulness of the recent past.

(Robinson, 2003)

# Making the Distinction between *Retained Sexual Intimacy* and *Hypersexuality* (Robinson, 2003)

The assessor asks the question:

*“Would this behavior be inappropriate if it occurred in private?”*

↓  
*No?*

↓  
*Provide Privacy*

# Interventions – Educational

## Interventions

1. Staff development specifically targeted to sexual behavior in the dementia context.
2. Staff development must be inter-professional in focus.
3. Case study discussion and group care plan development essential.

(Heath, 2011; Lichtenberg, 1997; Tzeng, et al., 2009; Wallace, 2006; Ward, et al., 2005)

# Interventions – Environmental

## Interventions

1. Private spaces available that have easy access.
2. “Do not disturb” signs.
3. Private space for conjugal visits.
4. Double beds as an option.
5. Photographic images that convey messages that accept love and intimate relationships.

(Heath, 2011)

# Interventions - Policy

## Interventions

1. Clearly developed policies and practice guidelines.
2. Well thought-out definitions for sexual behaviors.
3. Need for referral for assistance with assessment and intervention development must be based on clearly identified criteria.
4. Organizational leadership around this sensitive clinical problem is essential.

(de Medeiros, Rosenberg, Baker, Onyike, 2008)

# Interventions – Pharmacological

## Interventions

1. Neuroleptics and benzodiazepines are commonly used – usually ineffective and poorly tolerated due to side effects (Stewart & Shin, 1997).
2. Atypical antipsychotics thought to be tolerated more due to lower risk of side effects – little evidence of effectiveness (Lantz & Marin, 1996).
3. Treatment with SSRIs may be effective due to antilibidinal effect (Stewart & Shin, 1997).

# Unpacking Successful Verbal Intervention in the Intimacy Context

1. **Validating** the person's reality and emotional state.
2. **Joining** in with that person's reality and listening to her/his individual perspectives.
3. **Reframing** is then easier and works best with individuals who are anxious or puzzled about their place in the world.
4. **Identifying Goal & Tailored Strategies** may finally be possible without dismissing/extinguishing the person's original emotional response. The goal is resolution and transition, not "telling the person how to be or what to do."

*"George, it seems like you are really missing the companionship of your wife right now."*

*"George, tell me more about your wife, and your feelings about her."*

*"George, it must be hard to sleep alone at night after 50 years with your wife. She and your sons are all rooting for you and asked me to tuck you in."*

*"I will get you another blanket to help you feel nice and cozy."*

# Possible Practice Implications

1. Intimacy-seeking – (associated with AD, moderate – severe)

Treatment –

1. Behavioral programs that provide richer interpersonal experiences, shared social activities and companionship

2. Staff education and professional development

2. Disinhibited – (associated with non-AD, mild)

Treatment –

1. Pharmacological interventions could have high value

(de Medeiros, Rosenberg, Baker, Onyike, 2008)

# Assessment Concerns

1. Voluntariness – no coercion
  2. Safety – STIs, physical harm, psychological harm
  3. No exploitation
  4. No abuse
  5. Ability to say “no”
  6. Socially appropriate time and place
- (Collopy, 1988; Lichtenberg, 1997; Lyden, 2007)

**Retirement home had family meetings and used these guidelines to make the following decision → Sleep together in female resident’s room (double bed)**

# Sexual Expression in the Dementia Context

- Determine risk of exploitation
- Determine mutuality
- Involve family
- Primary moral obligation in response to sexual expressions of people with dementia is to prevent humiliation (privacy and dignity)

(adapted from Holstein, 2005)

# Levels of Sexual Behavior

- Level I – Intimacy/Courtship behaviors
- Level II – Verbal sexual talk
- Level III – Physical sexual behaviors directed toward self, or toward co-residents who are in agreement
- Level IV – Unwanted, overt physical sexual behaviors directed toward others
  - (Adapted from Sloane, 1997)

# Decision Tree for Assessing Competency to Participate in an Intimate Relationship

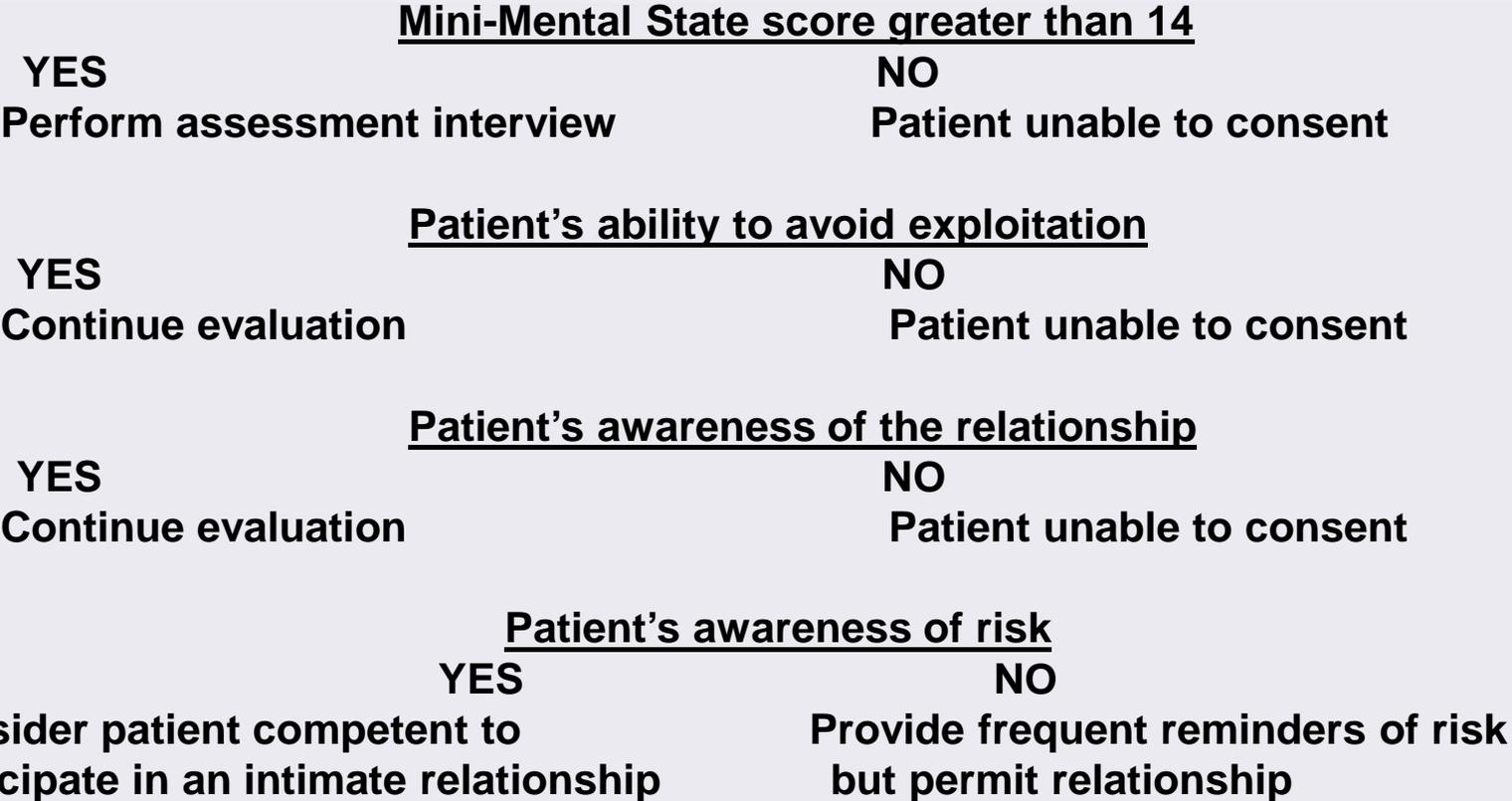


Figure 3. Linear decision-making schema (present state of literature with respect to dementia) (Lichtenberg, 1997)

# Talk to the Resident

- Is the resident aware of the relationship?
- Can the resident state what level of intimacy he or she would be comfortable with?
- Is the resident able to avoid exploitation?
- Does the resident have the capacity to say no to any sexual overtures?
- Is the resident aware of the social context within which the relationship is occurring?
- Is the resident aware of the risks involved in the relationship?

(Adapted from Lichtenberg, 1997)

# World Health Organization (WHO)

The right of all persons, free of coercion, discrimination and violence, to decide to be sexually active or not; engage in consensual sexual relations; choose a partner; pursue a satisfying, safe and pleasurable sexual life...

(WHO, 2010)

# In summary, formal caregivers must:

1. Act within defined legal frameworks and expected professional conduct codes;
2. Strive to promote and support human rights, dignity, privacy and choice;
3. Conduct comprehensive assessments, including risk;
4. Acknowledge that assessments will not always be “straightforward”;
5. Solicit views from a range of people;
6. Seek specialist advice where appropriate.
7. Expand knowledge and practice competencies.
8. All viewpoints must be considered.

(Heath, 2011; RCN – [www.rcn.org.uk/development/publications](http://www.rcn.org.uk/development/publications))

# THANK YOU!!

## ANY QUESTIONS???

**If you have any questions or would like further information about the sexual health of older adults in the dementia /nursing home context, please contact:**

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