Intimacy and Sexuality in Dementia

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Why the bath tubs?
Audience Response System Practice:
Dr Smith gave this talk last year

1. I came last year and came back because it was so good
2. I was here last year and came back because it was so bad
3. I was not here last year
4. I’m not really here this year
1. Person with cognitive impairment (CI)
2. Partner to a person with CI
3. Other Family of Person with CI
4. Professional direct care provider
5. Professional administrator
Sexuality in Maslow’s Hierarchy of Need

- **The need for self-actualisation**
- **Experience purpose, meaning and realising all inner potentials.**
- **Esteem Need**
  - The need to be a unique individual with self-respect and to enjoy general esteem from others.
- **Love and belonging needs**
  - The need for belonging, to receive and give love, appreciation, friendship.
- **Security Need**
  - The need for social security in a family and a society protects against hunger and violence.
- **The physiological needs**
  - The need for food, water, shelter and clothing
Personal Experience and Positive Emotional Value of Sexuality

• Expressing love
• Feeling loved
• Gaining pleasure
• Giving pleasure
• Gaining validation
• Giving validation
Sexual Behaviors at home

- Flirtation
- Touch
- Intercourse
- Masturbation
What percentage of women over age 75 remain sexually active?

1. 37%
2. 27%
3. 17%
4. 7%
What percentage of men over age 75 remain sexually active?

1. 37%
2. 27%
3. 17%
4. 7%
Sexually Active Seniors %

Lindau et al; 2007, NEJM
Personal Experience and Negative Emotional Value of Sexuality

– Abuse and Trauma
– Harassment
– Infidelity
– Addiction
Sexual Behaviors in facilities

- Flirtation/sexual talk
- Touch
- Intercourse
- Masturbation
Even the most confused individual affected by dementia is still a sexual being.
**Scenario 1:** John, a married man with moderate dementia, begins consoling Betty, a distressed widowed woman with dementia. Soon they are regularly sitting and walking together holding hands. Her distress is diminished.

1. I’m ok with that
2. I’m not ok with that
3. Depends on what the spouse thinks
John O’Connor Scenario

- Adultery?
- He believed that the woman was Sandra?
- He regressed to age where he was not married?
- He was too confused for any of the above?
Scenario 2: Direct care staff find John and Betty (from scenario 1) embracing alone in her room. Perhaps they have been kissing. Everybody appears a bit embarrassed.

1. I’m ok with that
2. I’m not ok with that
3. Depends on what the spouse thinks
Scenario 3: Direct care staff find John and Betty in bed together. Spouse has previously stated ‘I just want John to be happy’.

1. I’m ok with that
2. I’m not ok with that
Frequency of ‘sexual’ behavior problems in dementia

- 18% - Sexual aggression - Ryden (1988)
- 2.6-8% - Sexually inappropriate behaviors - (Harris and Weirs - 1998)
- 5-25% - ‘Inappropriate behaviors’ - (Ott et al, 2000).
  - Included sexual behaviors, noisemaking, smearing feces
  - increasing with dementia severity
  - no difference male to female
Sexual Behaviors

Intimacy Seeking

Disinhibited

De Medeiros et al., (2008)
Which person is most likely to be at risk for dismissal from your facility?

1. A woman that scratches and slaps during cares
2. A man the grabs breasts or buttocks during cares
3. Both are equally likely
4. Neither are at risk
Does your facility have a policy and plan for managing sexual behavior between residents?

1. Yes
2. No
3. I don’t know
Resident 1
Awareness
ability to consent
comfort

Resident 2
Awareness
ability to consent
comfort

Family/Decision-maker
- Values, beliefs
- Comfort level
- Education

Staff
- Standards of practice
- Values, beliefs
- Education

Law
- Vulnerability standards
- Care facility standards
- Criminal Code

Facility
- Values
- Environment
- Policy

fhs.mcmaster.ca/mcah/cgec/toolkit.pdf
Steps to Institutional Policy regarding Sexual Behaviors

1. Assemble a Team
2. Study the Issues
3. Focus groups?
4. Review other organizations’ policies
5. Create working definitions of key concepts
6. Pre-define interventions
7. Draft Policy
8. Implement Policy
9. Evaluate Policy

• fhs.mcmaster.ca/mcah/cgec/toolkit.pdf
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Level 1 Intimacy/ Courtship behaviors

- No risk associated with this behavior, if both persons consenting: Overall goal of staff response is to provide socially appropriate context for relationship that offers comfort and reassurance.
- This behavior is viewed primarily as an intimacy relationship between two adults that are mutually consenting, implied by behavior toward each other.
- Source of urgency associated with this behavior is usually staff and/or family discomfort. Staff may wish to protect family.
- The couple may need to have intimacy needs recognized and privacy respected. (Schofield, 2002)

LEVEL 2 Verbal sexual talk/language

- Low level of risk associated with this behavior:
- Often occurs during personal care.
- Staff to recognize their feelings of unease
- Respond respectfully.
- Punitive language not helpful
- Redirected into a more socially appropriate context.

LEVEL 3 Self-directed sexual behaviors

- Low level of risk.
- Assess for safety/health (e.g. excessive behavior may lead to skin/peri issues).
- Focus on creative solutions for the resident (this may include sexually-explicit materials &/or vibrators),
- Maintain privacy, dignity, safety and least restriction (Zeiss & Kasl-Godley, 2001).

LEVEL 4 Physical sexual behaviors directed towards co-resident with agreement

- Moderate level of risk associated with this behavior.

**SPRING INTO…ASSESSMENT**

- Is dementia sufficiently mild so the capacity to make decisions regarding basic needs and immediate gratification such as sexual activity is retained (Post, 2000).

- Any signs of sexual overtures that are actually unwelcome. Does one partner in the pairing look distressed, upset, worried?

LEVEL 4 Physical sexual behaviors directed towards co-resident with agreement

- What is the extent of sexual behaviors?
- Can the residents give an account of behaviors they would find acceptable/unacceptable?
- Do they have the ability to say “no” or indicate refusal and/or acceptance?
- Do they have the ability to avoid exploitation?

Assessing for Competency to Participate in a sexual relationship Lichtenstein 1997

- **MMSE > 14**
  - yes → Can avoid exploitation
  - no → Unable to consent

- Can avoid exploitation
  - yes → Is aware of relationship
  - no → Unable to consent

- Is aware of relationship
  - yes → Is aware of risk
  - no → Unable to consent

- Is aware of risk
  - yes → YES, YES!!
  - no → Caution about risk but
LEVEL 5 Unwanted, overt physical sexual behaviors directed toward others

- HIGH risk
- Response indicates person is objecting
- Staff to view it as an unwanted invasion of personal space
- Protect the resident/others from unwelcome sexual behavior
- Treat resident that is expressing overt sexual behavior with respect and dignity
- Be aware of the extent of sexual behaviors

Treatments: Pharmacologic

• “No randomized controlled trials exist for any treatment of sexual disinhibition in dementia and there are no trials comparing different pharmacological agents.”

Treatments: Pharmacologic

• **Serotonin reuptake inhibitors** - may be best when there is compulsive quality

• **Atypical anti-psychotics** - if there are psychotic or aggressive features

• **Mood stabilizers** - if evidence of hypomania, reduced sleep, pressured speech

• **Hormonal therapy** - ???

Treatments: Nonpharmacologic

• DBART Philosophy #2; ‘Cannot create a behavioral vacuum.
  – What behaviors will you increase?
  • Appropriate touch
  • Belonging…pet therapy, an inanimate object to ‘care’ for, reminiscing,
“Appropriate Touch”

- Hand shakes
- Holding Hands
- Massage
- Hair care
- Dancing
Obtaining a TeleDBART

- TeleDBART involves the use of a Skype video connection on a laptop we provide to enable the DBART team first to interview the resident or patient, and then to interact with staff and the resident’s family.
Obtaining a TeleDBART

- Call Julie at 507-285-2649 to Initiate referral
  - Fax relevant medical records
- DBART team reviews as necessary
- Appt Scheduled by Julie
- Computer shipped
  - to arrive at least 1 day in advance
  - with link to baseline data form
- Skype tested day before session
- Session with Bruce, Angela, Glenn
- Computer return
- Reports sent by Glenn and Bruce
- Follow-up email