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Sexuality, Intimacy and Dementia

Words Matter:

Intimacy:
- Intellectual intimacy
- Emotional intimacy
- Spiritual intimacy
- Physical intimacy
- Work intimate
- Intimate friend
- Intimate relationship
- Seeking an intimate relationship

Sex:
- Sexuality
- Gender
- Sexy
- Sexually aggressive
- Sexually acting out
- Sex talk
- Sexual intercourse
- Sex partner
- Masturbation

Eight Cases:

What do you think?
What is happening?
What should be done?
Bob and Sally Collins:
- 82 yo male and 75 yo female
- Married 60 yrs, moved in recently due to dementia of husband and increased elopement attempts
- Wife prefers to do his personal care, she argues that he is able to do more if he tries, and she doesn't want other women to touch him
- Kids have not been able to change mom's mind
- They are often found in the same bed during night time checks

John Jones and Mary Smith:
- 82 yo male and 79 yo female: both with Alzheimer's mid-disease
- Wife died 9 years ago, husband still alive
- No h/o aggressive or sexual issues for either
- Recently began approaching each other: they like to sit and cuddle, hold hands, kiss, walk together, she calls him by husband's and he calls her "sweetheart"
- She becomes angry and hits husband if touching
- John gets upset that she is upset

Harry Mason:
- 63 yo male with Pick's disease: few words and poor understanding, impulsive
- Tries to touch female caregivers when doing ADLs: puts hands in pants, unzips and urinates in hallways/corners
- Likes to give 'bear hugs' to all females
- Wife reports no h/o problems, although she is frustrated/embarrassed by his behaviors and yells at him
Sarah Holt:
- 79 yo widowed retired school teacher
- Mid-late disease: limited skills
- Approaches other females asks for a kiss and holds hands with any female, ignores males
- No immediate family: niece is POA
- Emerges nude from room in middle of night and early AM, tries to get in other’s beds

Don Gallo:
- 32 yo married male s/p head injury in Iraq
- Bed/chair bound: dependent in all care and mobility with R side paralysis
- He makes multiple sexual comments and attempts to touch and grab caregivers throughout care whether family is present or not
- He becomes very agitated with mouth care, perineal care, and finger sticks

Frank and Myrtle Booth:
- Married 60 yrs, both are in their 80s
- Frank has signs of beginning Alzheimers
- Myrtle is mid-late disease
- Frank wants to continue having sexual relations with Myrtle on a 3-5/wk basis
- She cries and tries to get away from him when he approaches her, but gets quiet when they are in their room
Fred Harper:
- 75 yo with Lewy Body Dementia
- Reports that staff are sexually attacking him at night and grabbing his ‘privates’ when they help him
- He wanders the building at night trying to enter rooms, calling for his wife who has been dead for 7 years
- Retired priest

Barbara King:
- 72 yo 3x divorced female
- Retired lawyer: no HC PoA
- H/o sexually active lifestyle
- Early in Alzheimers: very impulsive in speech and action
- Uses sexually explicit words/comments
- One daughter wants to support past
- One daughter wants it stopped

Why Is ‘It’ An Issue?
- They may lose ability to separate public/private
- It is not a topic most older adults are comfortable bringing up
- It is very personal and value-laden
- It can break families and friendships
- It can create a ‘placement’ problem
- It can affect care dramatically
- It can be life-threatening
- Ethical issues
- Legal issues
- Multiple points of view and value systems
- It’s complex!!!!!
Ethical Issues:
- Autonomy
- Dignity
- Equity
- Justice
- Beneficence
- Non-Maleficence
- Safety
- Privacy
- Social Expectations
- Health Care Proxy
- Sexual Abuse
- Sexual Harassment
- Sexual Exploitation
- Sexual Orientation
- Lifelong patterns
- Disease Alterations

Legal Issues:
- Competency
- Incompetence
- Guardianship
- Health Care POA
- Durable HC-POA
- Advance Directives

Dementia-Related Issues:
- Diagnosis
- Type
- Progression status
- Communication skills
- Historic versus present function and preferences
- Spouse role/ideas and other family
- Other residents and their families
- Staff
- Administrators
- MDs, NPs, PAs
- Regulatory officials
- Law enforcement personnel
- Legal system
Cognitive Changes with Aging:
- Normal changes: more forgetful and slower to learn
- MCI: Mild Cognitive Impairment: Immediate recall, word finding, or complex problem-solving problems
- Half these folks will develop dementia in 5 years
- Dementia: Chronic thinking problems in > 2 areas
- Delirium: Rapid changes in thinking and alertness, seek medical help immediately
- Depression/anxiety: Chronic unless treated, poor quality of life, “I don’t know” or “I just can’t” responses, no pleasure, can look like agitation and confusion

When it Comes to ‘Sexual Issues’:
Realize:
It takes two to tango…or tangle!

The Goal:
Learn to dance with your partners!

Coming to an agreement is actually better than winning an argument…in the long run

Being ‘right’ doesn’t necessarily translate into a good outcome for everybody involved
Deciding to change approaches and behaviors will require you to stay alert and make choices… it is work!

What are the Sexually Challenging Behaviors that get to you?
By managing your own behavior, actions, words and reactions, you can change the outcome of interactions!

Really Ask Yourself:
Is this Behavior truly a problem or
Is this a ‘So What’ Behavior?
‘So What’ Behavior: an ‘annoying’ behavior that is not risky or dangerous
Is it a Sexually Risky Behavior?

- Risk to that person (physical, emotional, physiological risk)?
- Risk to caregivers?
- Risk to others?
- Is the risk real and immediate?
- Is it a possible or potential risk?
- Is it about sexual behavior, or not?

If it is a ‘So What’ Behavior:

- Can we agree to leave it alone!
- Figure out how to let go of it …
- Then let it go!

If it is Truly Risky:

Call the team together and work on problem-solving
Describe the behavior objectively:
- Who?
- What?
- Where?
- When?
- What helps and what makes it worse?
- Frequency and intensity?
Use the Six Pieces of the Puzzle:

1. Personal history and preferences
2. Level and type of dementia
3. Other health conditions and sensory losses
4. Environmental conditions
5. Care partner approach and behaviors
6. The day and how it all fits together

To Cope with Challenging Sexual Behaviors:

- Where will you start???
  - An idea:
    - Care partner education
    - Care partner skill building

Then:

- Observe and document the risky sexual behavior thoroughly:
  - What is the pattern
  - When does it happen
  - Where does it happen
  - Who is involved
  - What is said, done, attempted
  - What makes it better and worse
Re-look at the problematic challenging sexual behavior:
- What does the person need?
- What is the meaning of the behavior?
- Do you understand the risky behavior better?

Make a Plan!
- Who will do what
- When will it be done
- How will it work
- What environmental change is needed
- What props are needed and where will they be

Implement Your Plan!
- Keep track of progress
- Document what is happening
- Communicate among the team members
- Rethink, if it isn't working
- Celebrate, if it is!
What Should We Do?

- Start the conversation
- Open the dialogue
- Listen to one another
- Assess and explore, don’t assume
- Offer training sessions
- Educate staff and families
- Screen and ask
- Observe and consider
- Problem solve, don’t assume

Specifically?

- Offer training sessions
- Educate staff and families
- Screen and ask
- Observe and consider
- Problem solve, don’t assume
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