Intimacy and Sexuality in Dementia

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Why the bath tubs?
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

1. The physiological needs
   - Need for food, water, shelter and clothing

2. Security Need
   - Need for social security in a family and a society that protects against hunger and violence.

3. Love and belonging needs
   - Need for belonging, to receive and give love, appreciation, friendship.

4. Esteem Need
   - Need to be a unique individual with self-respect and to enjoy general esteem from others.

5. The need for self-actualisation
   - Experience purpose, meaning and realising all inner potentials.
Personal Experience and Positive Emotional Value of Sexuality

- Expressing love
- Feeling loved
- Gaining pleasure
- Giving pleasure
- Gaining validation
- Giving validation
Personal Experience and Negative Emotional Value of Sexuality

– Abuse and Trauma
– Harassment
– Infidelity
– Addiction
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
Maintaining sexual relations with a cognitively impaired partner

- Role change
- Issues of child like quality
- Issues of impulse management
For partners of those with cognitive impairment only…

1. We were not sexually active before CI
2. We remain happily sexually active
3. We remain sexually active but I have reservations
4. We discontinued sexual activity since CI
Alzheimer’s disease changes forever the ways in which partners relate to each other.

It changes the behaviors and expectations in relationships that often have been nurtured for many years.
The Loss..

- The loss of the sexual relationship can be a major part of grief and sense of loss
- The loss of intimacy or ‘connectedness’ is a major part of the grief and loss
- Acknowledging and mourning the loss is important
“I became more of a caregiver and less of a romantic partner; it's very hard to be sexual when you are acting like the mother”

A Caregiver
Partner caregivers may feel…

• Guilt
  
  for refusing a spouse’s sexual advances
  for wanting a satisfying intimate relationship
  for simply wanting a personal life
  for wanting the burden to end.
Partner caregivers may feel…

• **Frustration:**

  with problems that arise during sex

  with demented partner’s inability to satisfy or appear interested in your sexual needs

  with the inability to relate to your loved one due to his/her diminished mental capacity.
Partner caregivers may feel…

• **Resentment**

  for having to suppress one’s own needs
  over your loved ones accusations of infidelity
  of your marriage vow to care "in sickness and in health."
Partner caregivers may feel...

• **Embarrassment or Confusion**
  – over changes in spouse’s behavior
  – by sexual advances by your spouse who no longer recall’s your name
The biggest transition for a spouse of someone with dementia is likely
 Loneliness over the emotional intimacy that has been lost.
“It’s tough losing a mate of 50 years (we even went to kindergarten together). Who does one talk to at home when there is no rational response? Who gives emotional support? It is being married without being married.”

A caregiver
Coping... *Taking Care of your Whole Person*

- Develop a support system, the more the better, but include one person you can depend on in times of crisis.
- Keep a journal
- Feed your inner-self
  
  Plan your day so that a part of the day belongs to you

Take care of your physical body

Resolve to spend social time
Make a wish list
Spend time with people who make you laugh and appreciate you
Determine to make the best of a cruel situation. Your decision will energize you.
Give yourself permission to fail.
Find new ways to be intimate
Sexual Behaviors in facilities

- Flirtation/sexual talk
- Touch
- Intercourse
- Masturbation
Scenario 1: A family member with moderate dementia, begins consoling another resident in the facility where they live. Soon they are regularly sitting and walking together holding hands. Their distress is diminished.

1. As a spouse I’m ok with that
2. As a spouse I’m not ok with that
3. As a non-spousal family member I’m ok with that
4. As a non-spousal family memory I’m not ok with that
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 your family member embracing another resident alone in a bedroom. Perhaps they have been kissing. Everybody appears a bit embarrassed.

1. As a spouse I’m ok with that
2. As a spouse I’m not ok with that
3. As a non-spousal family member I’m ok with that
4. As a non-spousal family memory I’m not ok with that
Scenario 3: Direct care staff observe your family member masturbating in public areas. They request permission for provide ‘tools’ to encourage him/her to engage in these behaviors in the privacy of her/his bedroom.

1. As a spouse I’m ok with that
2. As a spouse I’m not ok with that
3. As a non-spousal family member I’m ok with that
4. As a non-spousal family member I’m not ok with that
Sexual Behaviors

Intimacy Seeking

Disinhibited

De Medeiros et al., (2008)
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
Barry Petersen

• Book
• Picture
Meeting my intimacy needs

• I am a male spousal caregiver and I would not consider seek intimacy outside my marriage (OMM)

• I am a male spousal caregiver and I have considered seeking intimacy OMM

• I am a male spousal caregiver and I have obtained intimacy OMM

• I am a female spousal caregiver and I would not consider seek intimacy outside my marriage (OMM)

• I am a female spousal caregiver and I have considered seeking intimacy OMM

• I am a female spousal caregiver and I have obtained intimacy OMM

• I am not a spousal caregiver
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