Exploring Issues about Sexuality & Dementia:

Assessing and Mitigating Risk

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brainXchange Webinar

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Declaration

- I am an advanced practice clinician, not a lawyer
- I am speaking from the context of my practice in facility-based care

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Your Questions

1. Why is the topic of sexuality and dementia a “struggle”?
2. How do we distinguish between sexual touch and the normal social touching that is **(should be)** part of the human condition? Is normal social touching reportable as abuse?
3. How do we manage relationships when residents with dementia attach themselves to another resident, especially if the spouses come for daily visits?
4. How do we address the sorrow that spouses feel when they see a spouse attached to another resident?
5. What about capacity for consent regarding this subject?

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Why is this topic important?

- Growing demographic of older persons
- Growing demographic of older persons with dementia
- Growing demographic of older persons with dementia who will live in facility-based care at some point in the progression of their disease
- When people live together in a neighborhood → they form attachments
- Attachment is expressed as kissing, caressing, fondling, petting, intimate touching

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Sexuality: Why is this topic a struggle?

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

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Sexuality: Why is this topic a struggle?

- Contributing factors to the sexual experience
  - Highly individualized
  - Family of origin
  - Gender
  - Developmental stage
  - Aging
  - Wellness/Illness
  - Environment (psychic)
  - Triggers (leather, flowers and chocolate)
  - **I love you with all my *Brain* (hippocampus, limbic system, amygdala and as in accordance with the law, my intact neocortex)**

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Sexuality: Why is this topic a struggle?

(Safe and Acceptable) Intimacy and sexual expression rests upon:

- The capacity **to know what one thinks** and feels
- The willingness to say it or show it to another
- The capacity to express feelings and ideas
- "I feel and relate, therefore I am" (Post, 2000)

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Sexuality: Why is this topic a struggle?

This is the picture of a playground, and…it just…it makes me think about how the **elderly revert back to childhood**, and **act like little kids**, and so…when I saw the playground, life just seems so **simple**, there are **no time constraints or anything**, and…if they're **pleasantly confused**, it's just, it's like the child - **they're innocent**. So that is why I chose to take this photograph…the elements of the **playground atmosphere is peacefulness, safety, it's innocent**.

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Values/Beliefs/Attitudes: An important 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 within the chronic illness context may be less than expected.
5. **People living with cognitive impairment continue to have sexual feelings.**
6. **People living with cognitive impairment are capable of normal sexual activity.**

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

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Research indicates that sex will:

- Increase overall quality of life
- Enhance self-esteem
- Contribute to healing from depression
- Enhance overall energy (Wallace, 2008)

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The World Health Organization (2010)

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Conditions for a healthy sexual relationship

- Safety, comfort, attraction
- Feeling secure and positive about the relationship
- A positive self-image, including feeling comfortable with one's body and sexuality
- Communication in general; about sex in particular
  (but the research tells us most of the communication during sexual negotiation is "unspoken", nonverbal)

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Five domains of sexual behaviour

- **Resident – resident**
- Resident – family **(more likely in community)**
- **Family – resident**
- Resident – staff
- **Staff – resident (Crystal clear → constitutes abuse)**

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Duty of care

Must address:

- **Practice policy with fulsome definitions:**
  - **Social behavior, neighborly behavior, friendship behavior, sexual behavior – the distinctions must be clear**
- **Assessment of sexual behavior:**
  - **Measures, including DOS – frequency, intensity and duration**
- Provisions for safe sex
- Privacy
- Protect vulnerable older adults
- Educate and counsel families
- Professional development for ALL staff

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Sexual consent and enactment

Desire → Want → Willing → Capable → Able

Able means:

mobile
dexterous
nimble
flexible
persistent

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Context of sexual consent in dementia

- Absolute control over who touches their body and how
- Lack of resistance must not be equated with consent
- Sexual consent includes **EVERYTHING**, not just penile penetration
- Sexual consent cannot be contemporaneous and cannot be given in advance for touching that occurs when the partner lacks capacity
- Sexual consent cannot be given by one person on behalf of another
- **No implied consent for anyone ever**
- **No SDM can consent to sexual activity on behalf of another individual**

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Sexual consent in the dementia context:
Depends on your social capital and gender?

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Abuse prevention and response

20. Every licensee shall ensure that there is in place a written policy to promote **zero tolerance of abuse and neglect of residents**, and shall ensure that the policy is complied with. 2007, c. 8, s. 20 (1).

(2) At a minimum, the policy to promote zero tolerance of abuse and neglect of residents,

(a) shall provide that abuse and neglect are not to be tolerated;
(b) shall clearly set out what constitutes abuse and neglect;
(c) shall provide for a program, that complies with the regulations, for preventing abuse and neglect;
(d) shall contain an explanation of the duty under section 24 to make mandatory reports;
(e) shall contain procedures for investigating and responding to alleged, suspected or witnessed abuse and neglect of residents;
f) shall set out the consequences for those who abuse or neglect residents;
(g) shall comply with any requirements respecting the matters provided for in clauses (a) through (f) that are provided for in the regulations; and
(h) shall deal with any additional matters as may be provided for in the regulations. 2007, c. 8, s. 20 (2).

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Fully consent? – Does it matter?

- "All the Way"
- Given at the time → SDMs CANNOT consent for sexual activity of another individual

Clear in law but difficult in practice

Have to be capable to assume risky decisions (but be able to "back out" at any point in time, and have to be "conscious")

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Sexual consent and incapacity

- Incapacity due to alcohol consumption – no particular blood alcohol concentration
- Incapacity due to cognitive impairment – 14/31 or below on a MMSE (Lichtenberg, 1997)

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Decision Tree for Assessing Competency to Participate in an Intimate Relationship

Mini-Mental State score greater than 14

YES — **Perform assessment interview**

NO — **Patient unable to consent**

Patient's ability to avoid exploitation

YES — **Continue evaluation**

NO — **Patient unable to consent**

Patient's awareness of the relationship

YES — **Continue evaluation**

NO — **Patient unable to consent**

Patient's awareness of risk

YES — **Consider patient competent to participate in an intimate relationship**

NO — **Provide frequent reminders of risk but permit relationship**

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

Consent

1. About decision-making
2. Capacity/Capability
3. Understood in context
4. Knowledge (about the issue in general sense) & consequences (about their own situation and impact of a particular action)

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Capable to do what?

- Degrees of capability
- Fluctuate, increase, decrease, day-by-day and moment-to-moment
- Focused in specific decision or kinds of decisions
- Ability of the person to understand risk → ?capable of assuming the risk?
- Ability to understand the information and appreciate the consequences VERSUS whether or not the person actually can ENACT the understanding and appreciation of the consequences in their own situation and at every moment in time (fine distinction)

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Clinical considerations

- The person has no sexual interest
- The person is sexually interested but has difficulty with performance
- **The person is sexually interested and performance able**
- The person is expressing loneliness in a sexualized way
- **The person is hypersexual**
- The person has sexual preferences/interests that have been suppressed throughout life

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Types of behavior

Three types of behavior evident

1. **Nonsexual –**
    1. Disrobing because of soiled clothing
    2. Climbing into another patient's bed
    3. Holding hands
2. **Retained Sexual Intimacy –**
    1. Appropriate sexual behaviours that occur in the wrong place
    2. Developing a close friendship with a co-resident, courtship/affection/attachment
    3. Masturbation
3. **Disinhibited/Hypersexual – ABUSE CONTEXT**
    1. Impulsive
    2. Indiscriminate
    3. Invasive, intrusive
    4. Opportunistic

(de Medeiros, Rosenberg, Baker, Onyike, 2008; Robinson, 2003)

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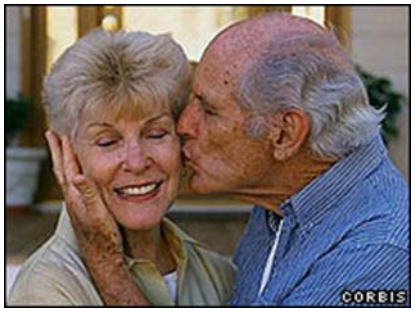
Comparative literature – Sexual offenders

1. Criminal Lifestyle – PERVASIVE pattern of rule violation and criminal versatility;
2. Sexual deviance – Problematic interest in sex that pervades psychological functioning;
3. Hostility – disposition toward violence often motivated by revenge schema;
4. Impulsivity – poor behavioral regulation;
5. Intimacy – frequent isolation despite a desire for emotional and physical closeness.

Assessment – What should we look for?

1. Voluntariness – no coercion, mutuality
2. Safety – STIs, physical harm, psychological harm
3. No exploitation
4. No abuse
5. Ability to say “no”
6. Socially appropriate time and place
7. Primary moral obligation in response to sexual expressions of people with dementia is to prevent humiliation (privacy and dignity)
8. Talk with the family



(Collopy, 1988; Holstein, 2005; Lichtenberg, 1997; Lyden, 2007)

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Talk to the person (Patient & Family)

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

(Adapted from Lichtenberg, 1997)

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Critical question

The clinical team asks the question:

"Would this behavior be appropriate if it occurred in private?" (Retained Sexual Behavior)

Yes?

Provide Privacy

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Hypersexuality – RISK FOR ABUSE

- **Key Features**

1. Directed at a number of people, NOT one particular relationship – **indiscriminate – PROVIDE OUTLETS FOR SEXUAL ACTIVITY**
   - **massage of the hands and feet, exercise, dancing, magazines, inflatable dolls, escort services**

- **Inherent Risks**

1. Increases likelihood of labeling and stigmatization

(Robinson, 2003; Miles & Parker, 1999)

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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 anti-libidinal effect (Stewart & Shin, 1997)

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)

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Case Study
Mrs. Irene Beckett (78 years)

- Attending a **support group for family** members of newly admitted residents to a nursing home
- Guest speaker – **maintaining relationship** with your family
- Wants **one-on-one meeting** **to discuss some things she is "struggling to understand"**
- Irene comes from a traditional background, homemaker
- Husband Bruce, pre-occupied with his work, and not attentive
- **Bruce spends a lot of his time "courting"** one of the other residents in the nursing home

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How to start the conversation with family?

- YOU must take the initiative
- Clients will take the lead from you…
  - if YOU are uncomfortable, they will be too.
  - If you are confident and open-minded, they will be too
  - To conduct a sexual health assessment with confidence → YOU are professionally obligated to discuss the topic and educate yourself how to do so (Rheaume & Mitty, 2008)

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Use the PLISSIT model

- **PERMISSION**
  - Encourage the person to talk about feelings of loss
  - Reassure the person that it is okay to participate in or refrain from sexual activity as THEY see fit
- **LIMITED INFORMATION**
  - Give information about expected physiological changes
- **SPECIFIC SUGGESTIONS**
  - Suggest non-sexual expressions of intimacy or ways to enhance opportunities for sex
- **INTENSIVE THERAPY**
  - Refer for individual counseling and Rx

  (Adapted from Rheaume & Mitty, 2008)

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The sexual health conversation should be structured as follows:

Phase One

- Introduction
- Open-the-door questions
- “What would you like to talk about today”?
- “Tell me your story; Tell me more about that; Go on; I’m listening; What happened next?”

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Emergent narrative

- Bruce was always busy
- I raised the children on my own
- We are not a close family
- Bruce was always critical
- Bruce was unattentive
- Bruce was, quite frankly, mean to me; he thought I was stupid, beneath him somehow
- Now he treats this woman with a tenderness I did not think him capable of
- **Why was he never kind to me?**

The conversation (cont'd)

Phase Two

- Four general questions:
- Please tell me about any concerns related to your (partner's) sexual health
- How has your (partner's) sexual functioning changed in the past six months
- How satisfied are you with your sex life
- How has your (partner's) medication or condition affected your sexual functioning

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Emergent narrative

- Bruce is developing feelings for this other woman:
  - Am I responsible for his behavior? Am I responsible to make sure he isn't mean to her like he's been mean to me?
  - Is this an "affair" that I should weigh in on? Should I forbid this relationship? Do I have a right to forbid it? Do I want to forbid it? I'm so angry with him.
  - What about this woman's family? Should I inform them about this situation? Do *you* do that?
  - Do I tell my children? What if they come in and find them together?

More conversation strategies

- Reassure
- Acknowledge feelings and concerns first
- Commend the person for their resilience
- Give support, educate, and collaborate to identify strategies

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More conversation strategies

You MUST acknowledge feelings and concerns first

"This sounds like a challenging time for you. Tell me more. What are you worried about? What do you think might happen? What do you think this situation/behavior/problem means?"

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Emergent narrative

- I must tell you, there is a man on our community library board who has asked me out to dinner several times:
- Should I go?
- I’m interested in him.
- What do I need to consider?
- Should I tell my children?

Emergent resolution

- There is no right or wrong answer
- The goal is to support the family member while they “figure it out”
- This takes time, and there will be a period of uncertainty that requires ongoing counseling and support
- Every LTCH should have a clearly identified “sexpert” resource who receives additional training

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Summary

1. Act within expected professional conduct codes and defined legal frameworks;
2. Strive to promote and support human rights, dignity, privacy and choice;
3. Conduct comprehensive assessments, including risk;
4. Acknowledge that assessments will never 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.

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Ethical considerations

Romantic and sexual feelings are long learned and deeply entrenched along with individual inhibitions and personality. There is nothing to suggest romantic or sexual desires or inclinations are any less valid when experienced by a person with dementia than when experienced by a person who is cognitively intact. It can be argued a desire for intimate relations is no different than a desire for certain types of food, or a good laugh. To deprive a person of being able to manifest their romantic and sexual interests in a mutually acceptable and congruent fashion is unreasonable ethically, and does not have any obvious merit legally.

(Gordon, 2004)

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Contact information

If you have any questions or would like further information about the sexual expression in the dementia context please contact:

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