

[Documenting*] Sexually Responsive Behavior:

Language has Meaning

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*** How we describe observed behaviors, influences interpretation and interventions**

Declaration

- I am an expert advanced practice nurse, ground level researcher and clinical educator
- My research and scholarship is grounded in the experiential-interpretive paradigm and informed by mixed methods
- I have over 25 years experience collaborating with inter-professional, transdisciplinary teams to address sexual behavior, intimacy needs and personhood/sexual identity as expressed by people living with dementia
- I have learned from each of these people, their families and their professional caregivers through this process of collaboration
- I believe that in all cases of sexual expression, with open, respectful conversation, proper evidence-informed assessment and inter-professional dialogue, an effective care plan can be developed and implemented with successful person-centred outcomes
- I believe that the world of exemplary best practice dementia care, by virtue of its complexity, is not black and white, thus the 'right' answer is never immediately apparent
- This requires courage, perseverance and innovative, complex, critical thinking

Practice conundrums

1. We operate in a value system that has not yet addressed the tension that exists between best practice guidelines and the legal requirements for duty of care
2. As a result of this tension, while we can distinguish clinically between sexual touch and the normal social touching that is *(should be)* part of the human condition it is difficult to make these distinctions and plan accordingly within present interpretations of the law
3. This presentation will focus on current understandings of sexual behavior, intimacy needs and sexual/personhood identities of people living with dementia

Why is this topic important?

- 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, fondling, petting, cuddling, hugging, intimate touching, stroking, caressing
- How should we speak about this, document this, interpret this and plan for this?

Why is this topic important: CONSENT

In Canada, substitute decision makers CANNOT give proxy consent for sexual activity of another individual

Clear in law but difficult in practice

Must create the space within which we can figure out best practice in each case:

Requires **DIALOGUE**

What should appear in this essential clinical dialogue?

Values & Beliefs to support practice:

- Need for touch, intimacy
- Feelings about oneself, one's body
- Need for intimate connections
- Sexual behaviors
- Desire
- Comfort
- Well-being
- Older people are SEXUAL BEINGS
- Older people hold SEXUAL IDENTITY



No touching at dinner



No touching in bed

Values/Beliefs/Attitudes: A moment for self-reflection



1. Sexuality is part of human identity.
2. Sexuality is a basic need in human experience.
3. Sexual expression is a component of health.
4. Expression of sexuality is a human right.
5. Decline in sexual activity within the chronic illness context may be less than expected.
6. **People living with cognitive impairment continue to have sexual feelings.**
7. **People living with cognitive impairment are capable of normal sexual activity.**



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



Research indicates that sexual expression in the dementia context will:

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



The *dialogue* must address the following questions:



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

The *dialogue* must include assessment of sexual behavior

Must address:

- Functional ability
 - Mobility, strength, balance, sequencing
- Cognitive ability
- Sexual history
- Physical exam
- Blood work
- STI status
- Direct behavioral observation and documentation



Location, location, location!



Documentation of sexual behavior Dementia Observation System (DOS)

- Presence, frequency, duration, severity, risk



Kissing?



Standardized Sexual Dementia Observation System (SSDOS)

Adapted from Dementia Observation System (Schindel Martin, 1998); deMedeiros et al. 2008; Robinson, 2003; Sloane, 1995

Use corresponding numbers to record in 30 minute intervals for a period of SEVEN days
(See definitions page for each of the categories. DO NOT add additional descriptors to this behavioral key. More than one number per square allowed.)

- | | |
|---|---|
| 1. Sleeping in Bed | 5. Retained Sexual Behavior – TO SELF (masturbation) |
| 2. Sleeping in Chair | 6. Retained Sexual Behavior – TO OTHERS |
| 3. Awake/Calm/Positively Engaged | 7. Intrusive Sexual Behavior – VERBAL (sexual slurs) |
| 4. Normal Interactive Behavior – COMFORT | 8. Hypersexual Behavior – PHYSICAL (overt sexual acts) |

YMD							
Time							
0730							
0800							
0830							
0900							
0930							
1000							
1030							
1100							

3	Positively Engaged
<i>For #3-8 check as you observe:</i>	
<input type="checkbox"/> Activity	<input type="checkbox"/> Singing
<input type="checkbox"/> Conversing	<input type="checkbox"/> Smiling
<input type="checkbox"/> Hand holding	<input type="checkbox"/> Hugging
4	Vocal Expressions (Repetitive)
<input type="checkbox"/> Crying	<input type="checkbox"/> Phrases
<input type="checkbox"/> Grinding teeth	<input type="checkbox"/> Questions
<input type="checkbox"/> Grunting	<input type="checkbox"/> Requests
<input type="checkbox"/> Howling	<input type="checkbox"/> Sighing
<input type="checkbox"/> Humming	<input type="checkbox"/> Syllables
<input type="checkbox"/> Moaning	<input type="checkbox"/> Words
<input type="checkbox"/> Other:	
5	Motor Expressions (Repetitive)
<input type="checkbox"/> Banging	<input type="checkbox"/> Pounding
<input type="checkbox"/> Collecting	<input type="checkbox"/> Rattling
<input type="checkbox"/> Fidgeting	<input type="checkbox"/> Rocking
<input type="checkbox"/> Pacing	<input type="checkbox"/> Rummaging
<input type="checkbox"/> Familiar/exit-seeking	
<input type="checkbox"/> Other:	
6	Sexual Expression of Risk
<input type="checkbox"/> Intrusive verbal expression	
<input type="checkbox"/> Intrusive physical expression	
<input type="checkbox"/> Hypersexual	

Every opportunity for:

1. Living a meaningful life
2. Companionship and intimacy



Resources

Supporting families and staff

- Alzheimer Society of Canada “Conversations About” Series – **Dementia, Intimacy and Sexuality**
- **Issues considered:**
 - Misinterpretation of behaviour as sexual
 - Changing needs of the person with dementia and their partner
 - Seeking companionship with a new partner
 - Having conversations about intimacy and sexuality
 - Strategies for responding to inappropriate sexual behaviours
 - Helping people with dementia and their partners maintain their intimacy in long term care
 - Supporting LGBTQ individuals living with dementia

Download your copy from:

www.alzheimer.ca/intimacyandsexuality

Resources

Supporting a 2-spirited, lesbian, gay, bisexual, trans or queer (LGBTQ-2spirit) individual with dementia

- **Understanding Gender**

Government of Canada & Status of Women Canada (n/a). *GBA+*.

<http://www.swc-cfc.gc.ca/gba-acsc/course-cours-en.html>

- **Seniors Pride organizations**

<http://www.the519.org/education-training/still-here-still-queer>

http://www.lgbtagencycenter.org/resources/pdfs/NRC_guidebook.pdf

<https://theconversation.com/its-time-to-end-the-taboo-of-sex-and-intimacy-in-care-homes-75740>

Upcoming research opportunities

‘Building capacity to support intimacy and sexuality in the context of dementia’

Aim: Develop an educational resource that will help individuals and long-term care homes support sexual expression for persons living with dementia.

Plan: Engage persons living with dementia, families, health care providers, administrators, practicing ethicists, and lawyers specializing in elder-law in discussions of their experiences and needs and development of resource.

Partnership: Between Alz Society of Toronto and Toronto Rehab Institute.

Team: Interdisciplinary team of academic and community-based researchers, professionals and experts, including family carers, a community agency providing support to persons living with dementia and their families and education to providers and administrators, an artist researcher, a practicing ethicist, and a lawyer specializing in elder-law.

Watch for: Recruitment and invitation announcements.

Beginning the Dialogue – Let's Talk



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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