“Seriously? At their age?...”

Sexuality and Intimacy in Long Term Care

Dementia Care 2019
Luana Whitbread RN CNS LTC Program
Objectives for Today

- Define Sex, Sexuality and Intimacy
- Understand Risk and Capacity to Decide
- Review 10 points about Sexuality/Intimacy in LTC
- Learn how to respond in ‘Real Time’
Sex

1. Either of the two major forms of individuals that occur in many species; distinguished respectively as female or male especially on the basis of their reproductive organs and structures.

2. The sum of the structural, functional, and behavioral characteristics of organisms that are involved in reproduction marked by the union of gametes and that distinguish males and females.

(Merriam–Webster dictionary, November 2018)
Sexuality

...is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.

...experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships.

(World Health Organization, 2010)
Intimacy

A close, familiar and usually affectionate or loving personal relationship with another person.

(Dictionary.com)
Intimacy and Sexuality

- ...Are basic human needs and are intrinsic to people’s sense of self and wellbeing.

- The need for intimacy for most people lasts until the end of their life.

(Kuhn, 2002)
Consider this …

“All individuals, regardless of their age or medical condition, need love, touch, companionship and intimacy”.

Canadian Family Physician reference 2013
- Sexual behavior tends to follow a life-long pattern, with behavior in younger adulthood a strong predictor of sexual behavior in older adulthood.

- Given that people have lived with their sexuality for longer than with their dementia, this likely holds true for those with dementia.
“Many people with dementia, particularly in the later stages, become less interested in sexual activity. This however may not diminish their need for human affection, touch and warmth”.  

(Bouman, 2002)
Sex and Ageism

- The aging body is ‘pathologized’...
  - Idea that aging is an ‘unwatchable’ process and that the older person is sexless or ‘de-sexed.’

- This attitude and the overall inattention to sexuality is a form of ageism
I did not realize until now, but my reaction to men and women is quite different. When I see an older man with dementia touching an older women I do tend to get quite angry, whereas towards the older women with dementia I feel quite protective and maternal towards them.”

-Staff person in LTC
In a study of residential care perspectives....the percentage of care givers who felt that sexual expression was a natural and/or expected aspect of the lives of a person with dementia living in residential care is........

7%
A word about ZONES

- **Public**: 25 ft
- **Social**: 10 ft
- **Personal**: 4 ft
- **Whisper**: 18 in

https://www.youtube.com/watch?v=gCAAy53cZDQ
The problem of definition…

‘An act of sexual expression holds meaning according to the perspective from which it is judged’

(Ward et al. A kiss is still a kiss? The construction of sexuality in dementia care: Dementia 2005;4: 49-72)
A word about “inappropriate”...

- What is considered appropriate or inappropriate will differ among individuals, institutions and cultures.
- It can be very subjective.
- Once an individual is labelled, they are labelled for the duration of their time in LTC.
- More important to focus on distress it causes rather than whether behavior is ‘normal’ or ‘appropriate.’
How Big an Issue is this??

- ‘Inappropriate’ sexual behaviours in elderly people with dementia are rare.
  (Chady Ibrahim & Christine Reynaert, Psychiatria Danubina, Vol.26, Suppl. 1 2014)

- ‘Inappropriate sexual behaviors are described in 3.8 to 7% of patients in institutions.
  (Derouesne, 2005)
Common presenting behaviors

‘Sex talk’
- Propositions to care givers when they are assisting with personal care

‘Sex acts’
- Public masturbation
- Undressing and exposing self
- Using obscene language and attempting to fondle caregivers

Implied ‘sex acts’
- Reading pornographic material
<table>
<thead>
<tr>
<th>Description of behavior</th>
<th>Level of Risk</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kissing, hugging, handholding, cuddling</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
  - Consensual (implies awareness of actions) | No risk if both parties consenting | Viewed as companionship |
  - Urgency with this behavior is usually staff or family discomfort |
  - Privacy may need to be respected |
## Determining level of risk

<table>
<thead>
<tr>
<th>Description of behavior</th>
<th>Level of Risk</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal sexual talk:</td>
<td>Low level of risk</td>
<td>Often occurs during personal care:</td>
</tr>
<tr>
<td>• Flirting, suggestive</td>
<td></td>
<td>▪ Causes discomfort &amp; reaction when directed to staff</td>
</tr>
<tr>
<td>or sexually laden</td>
<td></td>
<td></td>
</tr>
<tr>
<td>language</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Further comments

- Staff response is to recognize their own feeling of unease if contrary to their own personal values---- Important to respond respectfully.

- If suggestive language is directed at co-resident, staff or visitor---redirection is required.

- Stay away from punitive language: “Nice men don’t say those kinds of things to ladies…” ….Instead: “ John, would you like to have a chat? Tell me about…..”
## Determining level of risk

<table>
<thead>
<tr>
<th>Description of behavior</th>
<th>Level of Risk</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-directed sexual behaviors</td>
<td>Low risk</td>
<td>Physical causes:</td>
</tr>
<tr>
<td>- Masturbating</td>
<td></td>
<td>▪ Does resident have rash or full bladder</td>
</tr>
<tr>
<td>- Exposing oneself</td>
<td></td>
<td>▪ Rule out yeast infection</td>
</tr>
<tr>
<td>Context:</td>
<td></td>
<td>▪ Does the resident engage in this behavior in the presence of others</td>
</tr>
</tbody>
</table>
Further comments

- Focus on creative solution while maintaining privacy, dignity and safety

- Staff education might be necessary to remind staff to use the same infection control practices if required without judgement, ridicule or teasing
## Determining level of risk

<table>
<thead>
<tr>
<th>Description of behaviour</th>
<th>Level of Risk</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Physical sexual behaviors | Moderate:  
  - Risk increases immediately when sexual expression involves a partner |  
  ▪ Assess whether one partner looks distressed, anxious, upset  
  ▪ Be alert to sexual overtures that are unwanted or unwelcome |
## Determining level of risk

<table>
<thead>
<tr>
<th>Description of behavior</th>
<th>Level of Risk</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Non-consensual overt sexual behaviors directed toward others.  
  • Unwanted and rejected by the other | High risk | A resident may enter another’s personal space and behaviors may be unwelcome and upsetting for the person |
Further comments

- Watch for the response of the person that the behavior is directed toward.

- Staff response: goal is to protect the resident/others from unwelcome sexual behavior while still treating the resident with sexual behavior with respect and dignity.
QUESTION:
Are there policies regarding sexuality and resident care at your PCH or place of work?
Ethical Considerations

- Views on sexuality and the older person are often not a reflection of the values of the resident, but the values and attitudes of staff and the personal care home ...
  - At what point do we, as staff, have the right to decide what is ‘inappropriate’ touching?
  - How do we tell the family?
  - How do we decide whether a relationship will continue?
  - How do we determine capacity?
Defining Capacity to Consent to Sexual Relations

Questions to consider:

- Does the resident know who is initiating sexual contact?
- Does the resident believe the other person is a spouse or partner (when he or she is not)?
- Can the resident describe the level of sexual interaction they would be comfortable with?
Capacity to Decide:
Ability to Avoid Exploitation

- Is the behavior consistent with formerly held beliefs and values?
- Does the resident recognize the concept of choice and voluntariness?
- Does the resident have the information needed to make a decision?
- Does the resident have a substitute decision maker?
Capacity to Decide: Awareness of Potential Risks

- Does the resident realize that sexual contact may be time limited?
- Can the resident describe how they will respond if and when contact ends?
- Is the resident aware of any potential physical and emotional harm?
- Can the resident take precautions against risks?

(Lichtenberg and Strzepek, 1990 restated by Teitelman, 2002)
10 Points regarding *Sexuality in LTC*

1. Affections & intimacy contribute to overall health and wellbeing for people.
2. Some persons with dementia will have sexual or intimacy needs.
3. Some persons with dementia will have the capacity to make decisions about their needs.
4. If an individual in care is not competent to decide, the PCH has a duty of care to ensure the individual is protected from harm.

5. There are no rules that apply to all situations. Assess each situation on an individual basis.

6. Remember not everyone with dementia is heterosexual. “Gen Silent”
https://www.youtube.com/watch?v=fV3O8qz6Y5g
7. 'Inappropriate' sexual behavior is not particularly common in dementia.

8. Staff should confront their own attitudes and behavior towards older people and sex (sexuality and intimacy).
9. Look at how you can improve communication with your co-workers, managers, family and residents on this subject.

10. If you are having difficulty related to sexuality (in LTC), resident behavior and your personal response, be sure to discuss with someone.

Responding *at the time* to behavior of a sexual nature in LTC

from GMHT Clinicians Tip Sheet ‘Undesired expressions of Sexual Behavior’

- Avoid over reacting. Deal with any behaviors calmly and matter-of-factly. Try not to show embarrassment, shock, disgust, etc.
- Respect the dignity of all involved
- Try to reassure other residents or families that the individual means no harm.
Responding in real time (cont’d)

- Remember that the person with dementia may have no awareness that their behavior is ‘inappropriate’.
- Try to distract the person. Lead them to another location if they are in a common area and others find their behavior disturbing. Try getting them to focus on an alternate activity (Remind, divert, leave, return).
Responding in real time (cont’d)

- If you are staff, remind the individual who you are and why you are there/what you are doing.
- If the resident is touching you in a way you do not like, it is acceptable to tell them you feel uncomfortable.
- Learn about the resident’s history to better understand their current behavior.
- What are they trying to tell us?
## Misinterpretation?

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Possible Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clothing removal</td>
<td>Clothing-hot &amp; itchy</td>
</tr>
<tr>
<td>Self exposure</td>
<td>Need to use bathroom</td>
</tr>
<tr>
<td>Masturbation</td>
<td>Boredom/frustration</td>
</tr>
<tr>
<td>Inappropriate touch</td>
<td>Mistaken identity</td>
</tr>
<tr>
<td>Requests for kisses</td>
<td>Expressed need for touch</td>
</tr>
<tr>
<td>Attempts to fondle</td>
<td>Misinterpret others/ cues</td>
</tr>
</tbody>
</table>
A Review of key concepts...

- Sexuality and intimacy are basic human needs that do not disappear because a person has dementia.

- Staff should consider how their own attitudes and behavior toward older people and sex may influence the care they provide.

- Some behaviors that residents exhibit may be misinterpreted as sexual behavior when they aren’t.
Review of Key concepts (cont’d)

- Focus on the distress the behavior causes to individuals rather than whether behavior is ‘normal’ or ‘inappropriate’

- Factor in the level of risk when determining how to respond to different expressions of sexual behavior.