

Sexuality in Care Facilities

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Conflict of Interest Declaration



None





Educational Objectives



- Increase awareness of sexual expression across the lifespan
- Appreciate the barriers to sexual expression in care facilities
- Reflect upon decision-making in complex ethical situations
- Provide future directions for addressing this topic

Note on COVID-19





Outline



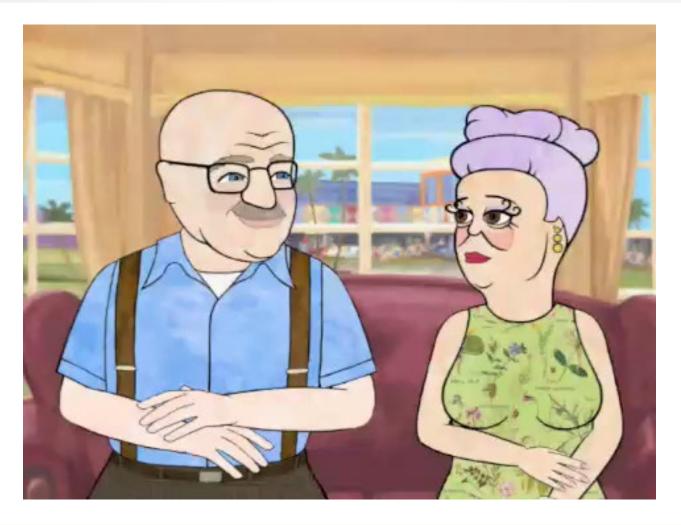
- Overview of sexuality
- Importance & Barriers
- Challenges
 - Cognitive impairment
 - Substitute decision-making
 - Changing values and beliefs
- Obligations and opportunities moving forward



Backseat Bingo (Liz Blazer)

https://vimeo.com/7584260?lite=1









Sexuality is...



- "...a central aspect of being human throughout life
- encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.
- experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.
- While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors." (WHO, 2020, my emphasis)

Adults reporting sexual activity (past 12 months) – "partnered"



	57-64 years	65-74 years	75-84 years
Men	85%	67%	39%
Women	62%	40%	17%

 Data from 2 nationally representative surveys of 3,000 adults in the U.S. (Lindau, 2010)



Table 1. Sexual Behaviors in the Past_Year by Gender and Age

	Male (Age		Female (Age)			
Variable	50-59 ^a	60-69 ^b	70+ ^c	50-59 ^d	60–69 ^e	70+ ^f
Masturbated alone	72.1%	61.2%	46.4%	54.1%	46.5%	32.8%
Masturbated with partner	27.9%	17.0%	12.9%	17.7%	13.1%	5.3%
Received oral sex from female	48.5%	37.5%	19.2%	0.9%	0.6%	1.5%
Received oral sex from male	8.4%	2.6%	2.4%	34.2%	24.8%	7.8%
Gave oral sex to female	44.1%	34.3%	24.3%	0.9%	0.9%	1.5%
Gave oral sex to male	8.0%	2.6%	3.0%	36.2%	23.4%	6.8%
Vaginal intercourse	57.9%	53.5%	42.9%	51.4%	42.2%	21.6%
Inserted penis into anus	11.3%	5.8%	1.7%	_	_	_
Received penis in anus	4.6%	6.0%	1.7%	5.6%	4.0%	1.0%

Note. Data are taken from the National Survey of Sexual Health and Behavior.

$${}^{a}n = 454$$
; ${}^{b}n = 317$; ${}^{c}n = 179$; ${}^{d}n = 435$; ${}^{e}n = 331$; ${}^{f}n = 192$.



- National Survey of 2,000 adults, aged 14-94
- (DeLamater, 2012)



Wide range of sexual expression





I'll read a good book for a good tingle, you know, like, a good romance novel... If you want love, get it from a book. It's a lot safer, you get a new guy every time, and you're not breaking your heart or anyone else's... I get the glow, the warm, fuzzy glow of love and intimacy through my books that I read. That's kind of my sexual expression these days." (Resident 12, female) (Brassolotto et al, 2020)

Essential to Health & Well-Being



Sexual activity: Weight loss, reduced risk of heart disease and stroke, pain relief, improved mood, and a bolstered immune system (Lindau, 2010)

Sexual expression and affection: Decreased pain sensitivity, increased relaxation, and lower levels of depression (Grigorovich & Kontos, 2016)

Love and intimacy: Maintains energy levels, contributes to longevity (Ehrenfeld et al, 1999), mental health, self-esteem, self-identity (Mattiasson & Hemberg, 1998) and quality of life (Flynn et al, 2016)



Connection to safety and belonging (Brassolotto et al, 2020)



"My mom wasn't a demonstrative person with hugs and saying, 'I love you,' even though we always knew that she did. It was interesting to watch her [in continuing care] hold another lady's hand and just stroke it... So, I think obviously, she needed that sexual expression in that case, to feel safe." (Family Member 7, female)





Connection to personhood and identity (Victor & Grimes, 2019; Mroczak et al, 2013)



"The emotional intimacy just makes me feel more as a person [sic]. Because I think without that, you can just sort of get lost in yourself." (Resident 6, female) (Brassolotto et al, 2020)



Risks



- STIs, pregnancy
- Falls, abrasions
- Emotional or social risks
- Abuse and exploitation
- Violence, discrimination



Sexual Health



- "a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.
- Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.
- For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." (WHO, 2020, my emphasis)



Maslow's hierarchy of

needs



morality, creativity, spontaneity, problem solving, lack of prejudice, acceptance of facts

Self-actualization

Esteem

Love/Belonging

Safety

Physiological,

self-esteem, confidence, achievement, respect of others, respect by others

friendship, family sexual intimacy

security of body, of employment, of resources, of morality, of the family, of health, of property

breathing, food, water, sex, sleep, homeostasis, excretion





- > Sexual expression is a human right
- > It is essential for health and well-being
- Sexual desire exists across the lifespan

And yet....

In continuing care facilities:

- Rates significantly lower
 - Multitude of barriers
- A lot of confusion, distress, and angst





Barriers to sexual expression



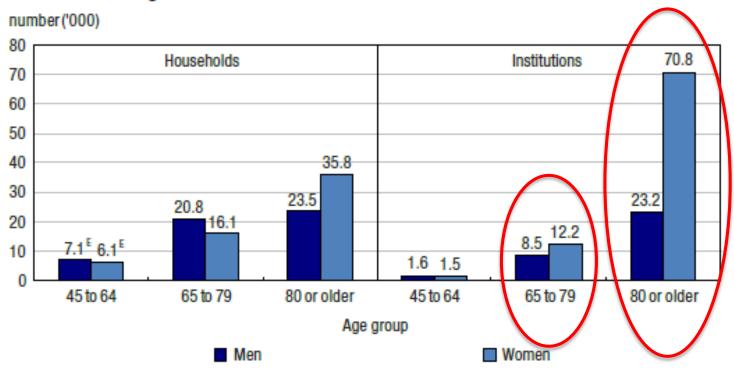


- Stereotypes
- Physical health
- Lack of available partner

Male-to-female ratios (CDN)



Figure 1
Number with dementia in private households (2010/2011) and long-term health care institutions (2011/2012), by age group and sex, population aged 45 or older, Canada excluding territories



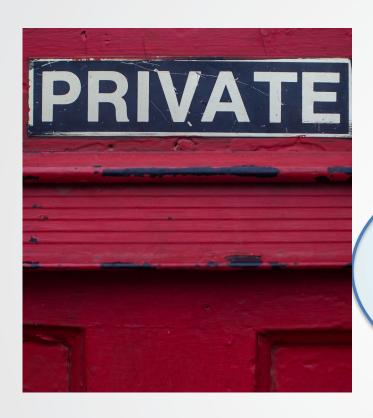
E interpret with caution

Sources: 2010/2011 Canadian Community Health Survey—Neurological Prevalence File (households); 2011/2012 Survey of Neurological Conditions in Institutions in Canada (institutions).



Barriers (2)





- Living in a care facility
- Lack of privacy
- Lack of policies

I want my dad to be able to watch porn. I mean, I don't want him to be able to watch porn, but I want him to be able to do as much as he can in his space that is his space (Family Member 1, female) (Brassolotto et al, 2020)



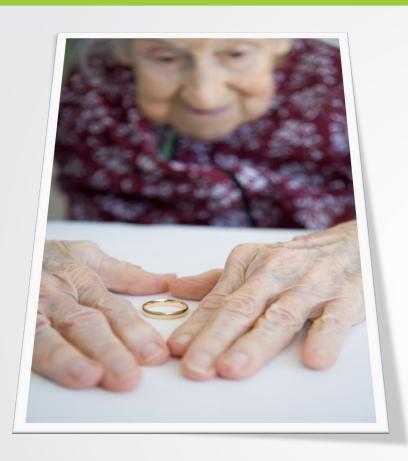
Barriers (3)

- Attitudes of staff and family members
- Homophobia or transphobia
- Impaired capacity



Sexual expression and dementia





- Desire and importance remain
- Pathologization and misinterpretation of behaviours
- Less supported by staff
- Paradigm of protection
- Changing values, preferences, behaviours, orientations

Decision-making around sexuality CLINICAL ethics





Adults with capacity



- Respect the choices of capable residents
- Capacity is decision-specific, on a continuum, can fluctuate
- Capacity for sexual activity (VCHA, 2009):
 - Have basic sexual knowledge, e.g. anatomy
 - Understand possible consequences
 - Ability to understand appropriate and inappropriate locations and times
 - Ability to express a choice and resist coercion [verbal or non]
 - Ability to recognize distress or refusal in a partner
- Sexual activity still permissible if criteria are not met (assessment required)



Adults with impaired capacity: traditional model



- Role of substitute decision-makers (SDMs):
 - Represent known wishes, values, beliefs of the adult
- Challenges:
 - Lack of clarity of role/scope for sexuality
 - SDMs are usually family members
 - Over-reach
 - Over-deference
 - Outcomes are often not resident-centred
 - Changing values, preferences, behaviours, orientations

Challenging scenarios – Values & Biases



#1 - Female resident is happy, flirtatious with several residents and intimate with one. Daughter says her mother was "prim and proper" her whole life and wants staff to stop her mother's behaviour.

#2 - Couple with an active sex life. Now the wife is in a facility with dementia. Spouse continues his loving visits. Wife seems distressed and ill-at-ease after his visits, and becomes agitated in advance of his visits.

- Weighing past behaviour and current experience
- Current benefits matter as well as current harms

Challenging scenarios – Values & Biases – cont'd

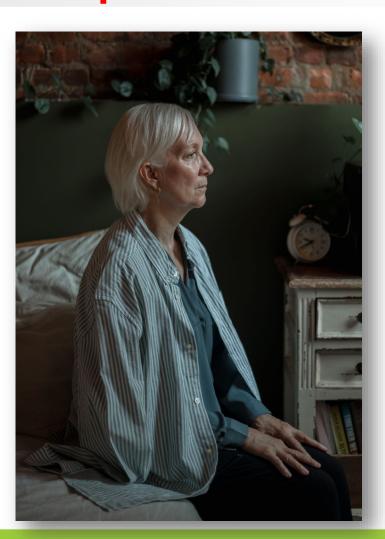


#3 – Male resident has been a strict, life-long vegetarian, repeatedly asking for meatloaf and enjoying it. His son wants staff to stop serving it to him.

- Do we hold moral commitments about sexuality to a different standard?
- How much should people be held to past commitments that they no longer hold?
- What constitutes harm (reputational, potential)?

Harms of restricting sexual expression





- Deprivation of benefits of sexual expression
- Exacerbating loneliness, helplessness, boredom; increasing frustration, distress, anger
- Demonstrating intrusion or overreach into private life
- Damaging sense of self, agency, personhood
- Generating stressful burden for health care providers

Another look at capacity and cognitive control impairment

- Broader scope for capacity
- Consent vs assent, willingness
 - Non-verbal
- Supporting sexual expression for incapable adults
 - Risk assessment & mitigation
 - Sexuality ≠ cognitive endeavour



Involving family members/SDMs



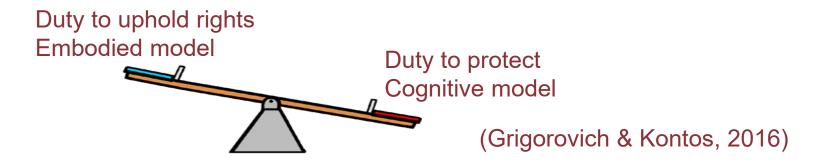
- Transparency, trust, privacy
- Determine purpose and rationale
- Shared decision-making, rather than deference



Change the narrative



Culture of promotion vs protection



 Ask "How can we make sex safe and possible for this resident?", rather than trying to control or limit sexual behaviour



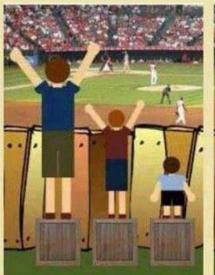
Obligations of care facilities



- Assess & intervene
 - Protect from exploitation and abuse
 - Mitigate risks
- Remove barriers, set culture
 - Pamphlets, intake assessment, inclusive language
 - Support privacy (of space, of body, of information)
- Promote opportunities
 - Provide care based on needs

- Develop policies
- Educate all parties

Equality doesn't mean Justice





This is Equality This is Justice



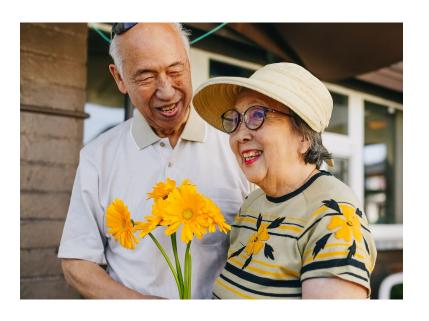
Summary



- Sexual expression is central to human-ness, health and well-being; not specific to cognitive status
- Residents have broader decision-making authority
- Engage in shared decision-making; range of values
- Remain resident-centred
- Culture shift from protection to support

Final Reflection





- Sexual expression remains overlooked, taboo and/or highly restricted in care facilities
- The pandemic has emphasized the need for human connection and the harms of loneliness and isolation
- How can we better support and enable meaningful sexual expression in care facilities?

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Discussion

Thank You!



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