Capacity to Consent to Sexual Expression in Long-Term Care

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Goals for the Session

- **Explore the complexities of defining consent amongst parties with diminished capacity**
- **Examine LTC residents' sexual rights & strategies for balancing resident autonomy with protection from sexual abuse**
- **Consider policies related to capacity to consent and the roles of the resident's interdisciplinary care team (ICT) & legal decision-maker**
- **Discuss benefits of collaboration among state entities**

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SEX

- **What is sex?**
  - **Difficult to define; no universally accepted definition**
  - **Subjective- sex means different things to different people; based on a multitude of factors**
- **Does sex matter to older adults?**
  - **YES. We don't "age out" of being sexual**
  - **Myths and preconceptions**

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Sexy Statistics

In the previous year	50-59	60-69	70-79	80+
Masturbated	54%	46%	36%	20%
Had intercourse	51%	42%	27%	8%
Received oral sex	34%	25%	9%	4%

(2009 national survey of 5,045 older adults, *Journal of Sexual Medicine* (2010))

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Is Sex Different for Older Adults?

In order to preserve residents' rights to sexual expression we must understand the meaning and value of sexuality in older adulthood

- **Hand holding**
- **Flirting/teasing**
- **Hugs, kisses**
- **Signs of companionship**
- **Romantic affection**
- **Masturbation**
- **Genital touch stimulation**
- **Intercourse**
- **Oral sex**
- **Anal sex**

Oftentimes, it 's more about affection and affirmation than acts of sexual gratification

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Sexual Expression in LTC

- **85+ population ⬆ to approx. 5.5 million in 2010; projected to ⬆ 6.6 million in 2020 (19% for that decade)**
  - **Transition from autonomy and independence in the community to greater dependence on others in LTCF is extremely difficult for many (without even considering the idea of sex)**

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Barriers to Sexual Expression in LTC

- **Residents face significant barriers to sexual expression in LTC environments**
  - **Lack of privacy**
  - **Lack of opportunity; partner**
  - **Fear of staff reaction; ostracism**
  - **Family attitudes; involvement**
  - **Physicians and healthcare providers**
  - **Few learning opportunities**
  - **Medication, health changes, cognitive decline**

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LTC Residents' Rights

- **LTC residents are guaranteed specific rights under the federal 1987 Nursing Home Reform Law**
- **Sexual expression is not explicitly stated, but several rights relevant to sexuality are addressed:**
  - **Privacy; confidentiality regarding personal affairs; right to make independent choices, personal decisions; to private, unrestricted communication with visitors of one's personal choosing; to be free from all forms of abuse and restraints**

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LTC Residents' Rights (cont)

- **Rights are enhanced by coinciding federal regulations (42 CFR 483.10)**
  - **Right to "dignified existence, self-determination, and communication with and access to persons/services inside and outside the facility"**
  - **More broadly, the right to exercise rights "as a resident of the facility and as a citizen or resident of the U.S."**
- **LTCFs must promote these rights in a manner that enhances QOL; ensures dignity, choice, and self-determination, while affording residents privacy to engage in safe, consensual sexual expression**

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Neurocognitive Disorders

- **Many illnesses alter or complicate sexual expression and initiate changes within the brain; therefore, are likely to cause changes related to sexual expression**

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Type of Dementia	Description	Effect on Sexuality
Alzheimer's Disease	• Most commonly known • Caused by plaques in the brain	• Mixed • Later stages of result in apathy.
Vascular	• Caused by poor blood flow • Stroke, diabetes, hypertension	• Usually results in apathy
Lewy bodies	• Abnormal protein deposits in nerve cells in the brain stem	• Unknown
Frontotemporal	• Pick's disease • Brain cell damage • Decline- social skills/emotional apathy	• May cause hypersexuality
Huntington's Disease	• Inherited • Impaired judgment, mood swings, depression, memory loss	• From lack of will to live to sexual disinhibition
Parkinson's Disease	• May not always result in dementia • Tremors, muscle tightness, speech problems	• Usually results in apathy • Medications may cause hypersexuality

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Adapted from Doll (2012) *Sexuality & Long-Term Care: Understanding and Supporting the Needs of Older Adults*, Health Professions Press, Inc. p. 101.

Dementia

- **Dementia affects approximately 47.5 million people worldwide, among which 60% are Alzheimer's cases (www.dementia.org, 2015)**

- **U.S. Dept. of HHS estimates nearly ½ of all nursing home residents have dementia (www.medicare.gov, 2009)**

- **Typically impacts the ability to control emotions, impulsive speech/actions (acting out, keeping private thoughts private), misinterpreted sensory information**

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Sexuality and Dementia

- **Increased sexual demands (17%)**
  - **Hypersexuality/Sexual Disinhibition- a clinically significant level of desire to engage in persistent sexual behavior; uninhibited behaviors that interfere with life (Series & Dégano, 2005)**

- **Presence of dementia at varying stages of severity poses challenges in determining capacity to consent**
  - **However, cognitive impairments don't necessarily eliminate one's ability for "recognizing their desire for intimacy and pursuing a meaningful relationship" (Hebrew Homes, 2011)**

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Reality Check

- **Ultimately, LTC facilities will face sexually-related situations involving residents (with and without diminished capacity) whether they're prepared or not**

- **Issues of consent arise when one or both partners has diminished cognitive capacity**

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Million Dollar Questions

- **Can an individual who lacks competency maintain the capacity to consent to sexual activity?**
- **Who gets to determine one's ability to consent?**

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Competency vs. Capacity

- **Competency vs. Capacity in Iowa Law**
  - **Competency: A legal finding conducted to allow the court to determine an individual's mental capacity**
  - **Capacity: the ability to understand the nature and effect of one's acts in a specific moment in time**

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Informed Consent

- **A 3-pronged test that requires an individual is: informed; gives consent voluntarily and; has the requisite capacity to provide consent**

- **In the context of a sex act, most jurisdictions consider a variation of these: Knowledge of the relevant facts concerning the decision to be made; Mental capacity, intelligence to realize & rationally process risks & benefits of engaging in sexual activity; Voluntariness to engage in conduct without coercion**

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Informed Consent (cont)

- **Every state agrees that a sex act occurring between two individuals where one lacks the requisite capacity to consent is a criminal offense**

- **However, the standard used in each state court to determine capacity and intelligence to rationally process the risks and benefits in order to consent varies**

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Competency Standards

- **Most states consider whether an individual has understanding of the nature and voluntariness of the sex act**
  - **13 states require an individual also be able to understand the consequences of the sex act**

- **Other states consider whether the individual understood the *moral* quality of the act, and whether there was evidence of a disability that would impact an individual's ability to consent**

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Competency Standards (cont)

- **Two states contemplate (through cognitive testing) whether the individual could exercise their judgment in making determination to engage in a sex act**

- **RESULT: The same individual may be found to have capacity in one state, but would be found to lack capacity in another**

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Capacity to Consent

- **Capacity- A fluid concept; an individual may have requisite capacity in one instance but lack it in another**

- **Does he/she have the ability to understand the nature and effects of his/her actions in a specific moment in time**
  - **Exhibit understanding and appreciation of the type of sexual activity: a description of the act, persons involved, risks/benefits associated with the activity, alternatives, understanding of rights to refuse**

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The LTCF's Role in Determining Capacity

- **First and foremost: LTCFs must assist residents in developing maximum self-reliance and independence; honor their right to choose what to do with their own body**
- **Enable residents to function at the highest possible level of social and emotional wellness**
- **Facilities: proactive vs. reactive**

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The LTCF's Role in Determining Capacity (cont)

- **Each sexual occurrence is unique and should be looked at individually and independently of others**
- **What does the resident want?**
- **In instances where the involved resident is cognitively impaired it may be necessary to involve a resident's family member or legal rep in the decision-making process**
- **However, NO SINGLE INDIVIDUAL should make the decision for another to have intimate relations**

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The ITC's Role in Determining Capacity

- **Where a resident indicates the desire to be sexually expressive, yet also exhibits signs of cognitive impairment:**
  - **The Interdisciplinary Care Team (ICT) must collectively assess level of capacity to determine relative benefits/potential harm (safety vs. risk) associated with the sexual expression (Hebrew Homes, 2013)**
- **ICT should *always* include Physician; may also include case manager, administrator, CNA/DCW, nurses, therapist (PT, OT, ST), social worker, activity director, family member, friend, pastor, legal decision-maker; depends on resident and circumstances**

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The ITC's Role in Determining Capacity (cont)

- **Cognitive assessment administered by the attending physician (continual, periodic; as needed per resident)**
- **Conversations with people who spend the most time with the resident; know them well**
- **Consult residents' care plans, files, notes, etc. to inform decisions (history, medications, patterns of behavior, changes in demeanor or health)**
- **Discuss sexuality with residents, families, staff**

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Decision-Making and Diminished Capacity

- **Substituted judgment: Using the person's past life, morals, judgments, values, etc. to determine what the most appropriate decision is for the person with dementia**

- **Best Interest: Using a general ideal of what would be best for any person in this position.**
  - **Most states are guided by the best interest principles in guardianship decisions**

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Crossing the Line: Sex and Criminality

- **Recent criminal proceeding in Iowa…**
  - **Jury instructions: A person lacks capacity to consent if the person was, "at the time of the sex act, mentally defective to the extent that the person could not understand the nature and consequences of the sex act, rendering the person unable to offer effectual resistance to the approach of persons who might take advantage of weakness"**

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Challenges to LTCFs

- **Liability of LTCFs in permitting or preventing sexual activities among the resident population**
- **Roles of family, staff, legal decision maker, guardian**
- **Crossing legal/ethical boundaries**
- **Considering whether sexual expression in LTCF can in fact, in many cases, be considered sexual abuse**
- **Validity/reliability- cognitive testing, assessment tools**

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Facility Sexual Expression Policies

- **General lack of sexuality policies in LTCFs today; though recent cases/media attention have increased awareness**

- **Facilities must establish proper management and response strategies; continuously provide staff support through training, in-services, discussions**
  - **Prepare residents, staff, and families for the occurrence of sexual expression among residents; share policies;**
  - **Educate on residents' rights and options related to sexual expression (resident/family council meetings)**

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Facility Sexual Expression Policies (cont)

- **Facility policy should clarify views on addressing residents' sexual needs/actions**
  - **Define appropriate/inappropriate sexual expression**
  - **Explain what constitutes sexual abuse; process for determining**
  - **Include education on safety/risks (STI's), the aging body, rules, ethics, and boundaries**
  - **Equip staff with the skills and knowledge to address situations properly and independently**

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Reality and Regulations

- **Is it possible to successfully reconcile facility, family, and resident expectations with federal and state laws and regulations?**
- **Of utmost importance- preserving the safety, dignity, and respect of the resident**
- **LTCFs must demonstrate they have gone through a thoughtful process in assessing risks and benefits; developing plan**

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Recommendations

- **Requirements for LTCFs to have a sexuality policy in place**
- **Mandatory training for professional licensure and staff training on the topic**
- **Establishment of multidisciplinary, multiagency taskforce or workgroup**
  - **Draw upon the knowledge of diverse entities and stakeholders to increase likelihood of positive outcomes for residents**

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Multi-Entity Collaboration

- **Iowa Sexuality Taskforce: All hands on deck!**
  - **Office of the State LTC Ombudsman, Dept. on Aging, Disability Rights Iowa, Dept. of Inspections and Appeals**
    - **Future- Dept. of Public Health, Dept. of Corrections**
  - **Purpose is to address important sexually-related issues that impact residents, provide guidance to LTCFs in developing sexuality policies, increase competency and consistency among LTC staff to ensure positive outcomes for residents**

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Multi-Entity Collaboration (cont)

- **Establish uniformity across disciplines, agencies, and facilities regarding acceptable approaches and expectations for creating LCT environments conducive to honoring residents' rights to sexual expression**

- **Important to recognize and balance competing objectives and varying goals and ideologies of the various agencies involved in the residents' care**

- **Sexuality Policy Guidebook**

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Requirements Reform

- **Iowa OSLTCO proposed changes- Reform of LTCF Requirements (CMS-3260-P)**
  - **Recommend CMS includes language which secures residents' rights to be sexually expressive and requires:**
    - **Facilities utilize ICTs (to include resident and attending physician) to develop and implement a sexuality policy**
    - **ICT make recommendations regarding the residents' capacity to consent to sexual expression**
    - **Facilities establish consistent, ethical response strategies so sexual expression is facilitated in a safe, healthy manner**

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Thank You!

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