
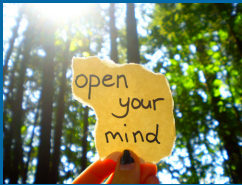


Sexuality and Intimacy in Dementia

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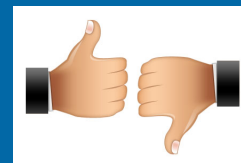
Disclosures

- Stanford University School of Medicine
- Geriatric Concierge Center
- Stanford Research Institute, International
- Covenant Care Company
- Sunnyvale Post Acute and Rehabilitation Center

Do you Agree?

- Sexuality is a basic human need
- Appropriate Sexual Behavior = Disease
- Sexuality in later life and its relationship to dementia is a neglected topic



Some Critical Questions:

- Can patients with Dementia have Sex???
- Are they capable of making a consent for Sex?
- What are the current policies now at LTCs?
- Have we trained people about it?

"Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, 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, ethical, legal, historical, religious and spiritual factors."

Intimacy

Quality of the interpersonal relationship among two people in a romantic interpersonal relationship, who may or may not be actively engaged in sexual activity.

Emotional intimacy or interpersonal satisfaction and subjective feelings of closeness.

Feeling of love or satisfaction when in the partner's presence or when thinking about the partner.

Sensuality

Experience of pleasure from one's senses leading to an increased awareness of and appreciation for one's own body. Such pleasure may be generated via sexual activity specifically, but also from any activation of the sensory organs.

It is essential to note that sensual pleasure can be experienced with or without another person.

Examples of sensual activities may include taking a hot bath or shower, noticing the breeze against one's face, having a massage, listening to music, lighting candles, getting one's hair done, eating a wonderful meal, molding or shaping clay, dressing up in beautiful clothing, splashing in puddles, lying in a feather bed, wearing silky underwear, singing in a resonant choral group, holding hands, using fragrant body lotions, dancing, engaging in foreplay, feeling muscles warm and loosen during exercise, or appreciating artwork.

Sexuality

Broadly based term that indicates any combination of sexual behavior, sensual activity, emotional intimacy, or sense of sexual identity.

Any individual's wish to engage in any of these activities also may be considered an aspect of sexuality.

Sexuality may involve sexual activity with the explicit goal of achieving pleasure (e.g., hugging, kissing) or orgasm (e.g., petting, oral sex, intercourse), sensual activity with or without the explicit goal of sexual pleasure (e.g., hugging, dancing, wearing body lotion to feel attractive or feminine), or the experience of emotional intimacy within the context of a romantic relationship.

What we are missing in our modern life



Where is the problem:

- Expression or Discuss about needs and Desire
- Private Subject
- Media



Found that among 3005, U.S. older adults who reports they are sexually active:

- 73% of adults aged 57 to 64
- 53% of adults aged 65 to 74;
- 26% of adults aged 75 to 84

Ulindeu ST, Schumm LP, Laumann EO, et al. A study of sexuality and health among older adults in the United States. *New Engl J Med* 2007;357:762-844.

Normal Sexual Behavior

Dementia

- Impacts all aspects of life.
- Dementia causes identity changes (infantilization of impaired Partner)
- New definition for relationship between partners.
- Uncertainty or Ambivalence in to the relationship.
- Expression of their sexuality may result in behaviors that are challenging to manage.



- Partner for no longer being able to provide the necessary care . Together with the physical distance, this might affect his/her perception of being either a 'We' or an 'I'.

* Kasten, L. (2001). A couplehood typology for spouses of institutionalized persons with Alzheimer's disease. *Perceptions of "We" / "I". Family Relations*, 50(1), 87-98.



- Older residents—with and without dementia, nevertheless, still think about sex and sexuality .
- While some wish to express their sexuality physically, others mainly associate sexual activity with the past surrounding it with nostalgia .
- Not only is sexuality highly individual, nursing home residents also consider it to be strictly personal in the sense that outsiders should not meddle.

* Bauer, M., Finkenrath, G., Tietz, J., Neuf, R., Weikert, D., & Beutler, E. (2013a). 'I dream back under the bed for a man': Needs and barriers to the expression of sexuality in residential aged care. *The needs of residents with and without dementia. Psychogeriatrics & Geriatrics*, 18(2), 195-205.

No Privacy



More Issues:

- Normal sexual behaviors such as masturbation or attempts to participate in consensual sexual relations may be perceived as hypersexual.
- Sometimes even in cognitively impaired people sexual behavior is normal but occurs in wrong place.
- For example, residents may confuse public and private areas or misidentify strangers as their spouse or partner

Also a major issue



CAPACITY

Individual's physical or mental ability relative to a specific task

COMPETENCY

Legal Incapacity is a legal status determined by a court that an individual lacks sufficient ability to make personal or financial decisions for her or himself.

Fundamental Rights for LTCs

1- Respect for persons, resident autonomy, and privacy, LTC residents have a right to appropriate accommodation for consensual sexual relationships.

2- All persons have the right to not have unwanted-to sexual aggression directed at them.

The Washington Post
Morning Mix

**Former Iowa legislator
Henry Rayhons, 78, found
not guilty of sexually
abusing wife with
Alzheimer's**

By Sarah Kaplan April 23, 2015

This post has been updated.

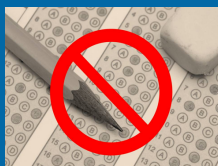
Whatever happened at the Iowa nursing home where Henry Rayhons was accused of having sex with his wife, an

Can A Person With Dementia Consent to Sex?



Test the Capacity

- Current decisions which are consistent with longstanding.
- Values are changing over time.
- Clinicians must be aware of an individual's values and base a capacity determination on the individual's values, not on the clinician's values.



Legal Standard

There are no universally accepted criteria for capacity to consent to sexual relations (Lyden, 2007).

The legal standards and criteria for sexual consent vary across states (Lyden, 2007; Stavis et al., 1999).

The most widely accepted criteria

- ❖ **Knowledge** of relevant information, including risks and benefits
- ❖ **Understanding** or rational reasoning that reveals a decision that is consistent with the individual's values (competence)
- ❖ **Voluntariness** (a stated choice without coercion) (Grisso, 2003; Kennedy, 1999; Stavis, 1991; Stavis et al., 1999; Sundram et al., 1993). In light of the variation in standards across jurisdictions

Lyden Assessment

- **Knowledge**
 - Presence of a choice to engage or reject the activity
- **Rationality**
 - Ability to critically weigh pros and cons
- **Voluntariness**
 - Able to protect themselves against unwanted intrusions, abuse and exploitation

• Lyden M. Assessment of Sexual Consent Capacity. *Sex Disabil* 2007;25:9-20.

ABA/APA /Lichtenberg Q

- 1- Patient's awareness of the relationship
- 2- Patient's ability to avoid exploitation
- 3- Patient's awareness of potential risks

Lichtenberg P, Strzepek D.

Assessments of institutionalized dementia patients' competencies to participate in intimate relationships. *Gerontologist* 1990;30:117-120. Cited in "Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists," 2006. American Psychological Association and American Bar Association, page 63. Available at: <http://www.apa.org/publications/assessments/assessments/assessments.htm>. Accessed 5/27/14.

Patient's awareness of the Relationship

- Is the patient aware of who is initiating sexual contact?
- Is delusion or misidentification affecting the patient's choice (eg, is the patient mistaking the other person for his or her spouse)?

Patient's ability to avoid exploitation:

Is the behavior consistent with formerly held beliefs/values?

Does the patient have the capacity to say no to uninvited sexual contact?

Patient's awareness of potential risks

Does the patient realize that this relationship may be time limited (placement on unit is temporary)?

Can the patient describe how [he/she] will react when the relationship ends?

Policy and Procedures at LTCs

Hebrew Home Sexual Expression Policy

ABUSE or INTIMACY: Older Adult Sexuality.

Assessing Consent to Sexual Activity in Older Adults

www.hebrewhome.org

Ability to express choices/consent

What are your wishes about this relationship?

Does your sexual partner make you happy?

Do you enjoy sexual contact?

Sexual Activity

Ability to appreciate

Do you know what it means to have sex?

What does it mean to you/your partner?

What would you do if you wanted it to stop?

What if your partner wanted it to stop?

Consider: Nature of the relationship (monogamous)

Emotion and mood, before and after sexual contact

Conclusion

- The right to engage in intimate sexual activity is a basic right for all older adults, including those with cognitive impairment.
- Capacity for sexual consent must be assessed in some manner for those with cognitive impairment in order to provide protection for them from non-consensual sexual aggression.
- No uniform standard for determination of sexual consent capacity in dementia



- Degrees of capacity required vary for increasing levels of intimate behavior, from simple touch to penetrative intercourse.
- Sexual consent capacity may wane over time, thus requiring serial assessments if consent capacity is deemed present in a cognitively impaired older adult.



Changes in the Future

- Sexual advance directives



Distinguish between normal sexual Behavior (consensual) and Inappropriate Sexual Behavior

Review a case:

Mr. Dementia is an 89-year-old man with moderately severe Alzheimer's disease who lives in your SNF as long term patient

He begins approaching female nursing home residents with sexual suggestions, which is upsetting for his family.

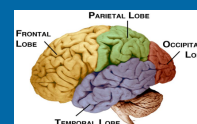
Despite a move to a different floor, he continues to make inappropriate verbal and sometimes physical sexual advances toward female residents and staff.

Inappropriate Sexual Behavior (ISB)

- Ethical and Medico-legal complex.
- Limited research and inconsistent definitions : ranging between 2% and 30%.
- men > women but whereas other sources suggest the behaviors occur equally.
- Gender has also been noted to influence the type of hypersexual behaviors, with men being more physically aggressive and women being more verbal.

Etiology

- Frontal and Temporal lobe
- Frontal lobe dysfunction impairs inhibitory sexual self-control mechanisms
- Temporal lobe dysfunction impairs emotional and intellectual understanding of sexual arousal.



Etiology

- Social factors, which may include loss of spouse or partner, lack of intimacy, and lack of privacy have been reported to contribute to hypersexual behaviors.
- Concomitant medical illnesses, including **urinary tract infections and cardiac disease**, may result in delirium, which is associated with hypersexual behaviors.
- **Medications** : Anticholinergics, benzodiazepines, anti-parkinsonian medications such as levodopa, and stimulant drugs such as cocaine

Reporting Hypersexual Behaviors by HealthCare Providers

- Delay or avoidance in the reporting of these behaviors results for several reasons:
- Studies suggest that underreporting of hypersexual behavior may be a result of caregiver or staff feelings of guilt, shame, or confusion when faced with sexual behaviors of residents.
- Lack of reporting of hypersexual behaviors not only results in possible negligence and mistreatment of residents, but delays or prevents accurate assessment and care planning.
- The tendency to underreport hypersexual behaviors underscores the importance of open communication between families and caregivers as well as the need for staff education and training to discuss values and discomfort in addressing sexual behaviors among residents

Higdon A, Barker P, Begley CM. Hypersexuality and dementia: dealing with inappropriate sexual expression. Br J Nurs 2004;13:1130-4.

Assessment of inappropriate sexual behavior

- What form does the behavior take?
- In what context?
- How frequent is it?
- What factors contribute?
- Is it a problem? For whom?
- What are the risks involved? To whom?
- Are the participants competent?

Adapted from Series and Dégano with permission from the Royal College of Psychiatrists. Series N, Dégano P. Hypersexuality in dementia. Adv Psychiatr Treat 2005;11(6):424-31.

After gathering the data

- Interview the resident in a quiet, private area to ensure that the older adult will not be overheard.
- The utmost respect
- Look for **Depression and Delirium (CAM)**



- Nurses may use patient's medical records to gather information from the past medical and social histories.
- Information from the minimum data set (MDS)

Also Looking for

- Mood disorder.
- Psychosis.
- Substance use disorder (Alcohol).
- Attention-seeking behavior.
- Long-standing hypersexual personality traits.

Nursing Assessment and Intervention

- Sensitive and creative nursing approach.
- Need IDT and involvement of family members.
- Comprehensive assessment : Detailed medical history, sexual history, and medication review

Look for Motivation

- For example, patients with dementia might fail to wear appropriate clothing in public simply because they have forgotten to get dressed or because they are too warm.
- In this case, it might be useful to provide the patient with clothing that opens in the back so that it cannot be easily removed.

Kamel HK, Hajjar RR. Sexuality in the nursing home, part 2: managing abnormal behavior—legal and ethical issues. *J Am Med Dir Assoc* 2004;5(2 Suppl):548-52.



Management

- Unfortunately, the literature is sparse and the few existing studies have important limitations.
- Most articles on this topic are based on single case reports or small case series.
- No randomized controlled trials (RCTs) have been published to establish the efficacy or safety of the many proposed treatments of ISB, and it is unclear in which order these treatments should be used when patients fail to respond to initial treatments.
- The generalizability of the existing literature is questionable; for example, most published case reports involve men, and it is uncertain how women might respond to some proposed treatments.

Non-pharmacological

- Removal of precipitating factors, distraction strategies, and opportunities to relieve sexual urges.
- In the nursing home setting, it might be necessary to separate a patient from another resident or staff member when the other person appears to be the trigger for ISB (eg, by reminding the patient of his spouse).
- Separation can be achieved by moving one resident to another floor in the nursing home.
- Distraction with other activities can sometimes help (eg., participation in crafts to occupy the hands and prevent inappropriate touching or public masturbation).

Bardell A, Liu T, Fedoroff JP. Inappropriate sexual behavior in a geriatric population. *Int Psychogeriatr* 2011;23(7):1182-8. Epub 2011 Apr 19.

Try to Distract

- Distraction with other activities
- Occupy the hands and prevent inappropriate touching or public masturbation



Referral to Specialized Geriatric Services

- Australian study
- Access to the multidisciplinary team was effective in reducing Dementia-related behavior and was associated with less use of psychotropic medications (level II evidence).



Bird M, Jones RH, Korten A, Smithers H. A controlled trial of a predominantly psychosocial approach to BPSD: treating causality. *Int Psychogeriatr* 2007;19(5):874-91. Epub 2007 Jan 19.

Creativity

- Emory Experience : a case report describes the provision of a 3-foot-tall stuffed doll to a man with dementia who was sexually aggressive toward women in his nursing home.
- His ISB stopped after introduction of the doll, as it provided an alternate means of sexual release (level III evidence).



Tate LJ, Rosenberg J. Neuropsychological treatment of inappropriate sexual behavior in dementia: the case of the pink panther. *Acta Geriatr Psychol*. 2008;16(7):612-3.

- Assisted living staff brought a 68-year-old white man to the Wesley Woods Hospital in March of 2005. He had a 4-year history of progressive dementia whose etiology could not be decided between Alzheimer's disease or frontotemporal dementia.
- The patient had prolonged periods of agitation, including **touching and grabbing the genitalia of female residents and staff**, over the past year.
- Prior attempts to address the agitated behaviors included isolating him from females and use of antipsychotic medication.

- Although the medications were effective in "slowing him down," they had little effect on his inappropriate behavior. He continued to select victims "at random," according to staff.
- In desperation, the patient **was given a stuffed animal for distraction. The animal was a 3-foot tall replica of the cartoon character, The Pink Panther.**
- The patient inappropriately grasped and fondled the Pink Panther, but he became less intrusive with fellow patients and staff. The patient was able to be discharged to a nursing facility.
- On telephone follow-up, staff reported that the patient continued his behavior of fondling the Pink Panther and had refrained from disrupting fellow residents.

Pharmacologic

- Antidepressant
- Antipsychotic
- Anti-androgens, Estrogens, GnRH
- Anticonvulsants
- Cholinesterase inhibitors
- H2 Blocker
- Antifungals
- Beta Blockers or Potassium sparing diuretics

Antidepressant drugs

- Main Side Effect: Sexual dysfunction
- SSRIs is effective, consider first line due to safety.
- In some case reports, paroxetine and citalopram had benefits within 1 week of treatment and lasting effects were observed at follow-up several months later
- Some reports showed Citalopram is ineffective.
- Remeron is only reported in one case.
- TCA is effective but

SSRIs (20 mg oral paroxetine once daily, 20 mg oral citalopram once daily)	Nausea, tremor, hyponatremia
15-30 mg mirtazapine nightly	Sedation, weight gain, myelosuppression
150 mg oral clomipramine once daily	Orthostatic hypotension, urinary retention, constipation, worsening cognition
100-500 mg oral trazodone once daily	Sedation, orthostatic hypotension, priapism

Antiandrogen

100-500 mg IM medroxyprogesterone acetate weekly	Fatigue, weight gain, hot or cold flashes, depression, elevated blood glucose, insomnia
10 mg oral cyproterone acetate once daily	Gynecomastia, galactorrhea, worsening diabetes control, depression, osteoporosis, adrenal insufficiency on withdrawal, hepatotoxicity (liver enzymes should be checked if it is used)
5 mg oral finasteride once daily	Gynecomastia, testicular pain, depression

- One report described successful use of low-dose oral cyproterone acetate (10 mg daily) for 2 male patients with dementia-related ISB that had not responded to treatment with antipsychotic or sedative medication (level III evidence).

• **Finasteride** is a 5 α -reductase inhibitor that blocks conversion of testosterone to dihydrotestosterone.

- This drug is commonly used to treat benign prostatic hyperplasia, and has the potential to produce low libido and erectile dysfunction. A case series describes use of finasteride to treat ISB in 11 elderly men with vascular dementia. Inappropriate sexual behavior disappeared in 6 of the 11 men within 8 weeks of treatment, the other 5 patients required alternative treatments (eg, propranolol, quetiapine)

1) Haussermann P, Goecker D, Beier K, Schroeder S. Low-dose cyproterone acetate treatment of sexual acting out in men with dementia. *Int Psychogeriatr*. 2003;15(2):181-6.

2) Na HJ, Lee JW, Park SM, Ko SB, Kim S, Cho ST. Inappropriate sexual behaviors in patients with vascular dementia: possible response to finasteride. *J Am Geriatr Soc*. 2009;57(11):2103-2.

Estrogens

0.625 mg oral conjugated estrogen once daily	Weight gain, depression, Gynecomastia and DVT
0.05-0.1 mg/d estrogen transdermal patch	
1 mg oral diethylstilbestrol once daily	

- Estrogens decrease secretion of luteinizing hormone and follicle-stimulating hormone, which lowers testosterone production and typically results in reduced libido.

- Lothstein et al describe the successful use of estrogen to manage sexual disinhibition in 39 elderly patients who had not responded to treatment with SSRIs (level III evidence). No adverse effects were reported but no time frame for response to treatment was described.

- Lothstein et al propose a treatment algorithm for ISB that begins with SSRIs (discussed above) and moves to either estrogen or antiandrogen treatment if behaviour does not respond to SSRIs.
- Another case report described using 1 mg of the synthetic estrogen diethylstilbestrol daily to reduce sexual aggression displayed by an elderly man with dementia (level III evidence)

Lothstein LM, Fogg-Waters J, Reynolds P. Risk management and treatment of sexual disinhibition in geriatric patients. *Conn Med*. 1997;61(9):609-18.

Leuprolide

- Gonadotropin-releasing hormone analogue
- Downregulates the secretion of LH and FSH
- leading to eventual suppression of ovarian and testicular steroidogenesis and reduced libido
- Case report describes the addition of leuprolide to propranolol in a patient with dementia who demonstrated a variety of behavior disturbances (level III evidence).
- Increased appetite resulting in substantial weight gain was reported.
- Leuprolide is expensive.

On B. Leuprolide treatment of sexual aggression in a patient with dementia and the Kluver-Bucy syndrome. *Clin Neuropharmacol*. 1995;18(5):443-7.

AntiPsychotic

1.5-3 mg oral haloperidol once daily	Sedation, extrapyramidal symptoms, falls, weight gain, ventricular arrhythmia
25 mg oral Quetiapine once	

Anticonvulsive

100-300 mg oral Gabapentin 3 times daily	Sedation, depression, ataxia, tremor
200 mg oral carbamazepine once daily	Sedation, depression, motor ataxia, hyponatremia, Stevens-Johnson syndrome, agranulocytosis, hepatotoxicity Use of carbamazepine requires monitoring with regular laboratory testing

Neurontin (Gabapentin)

- Case reports have described reduced sexual behavior in patients with dementia treated with Gabapentin (level III evidence).
- However, the medical literature about gabapentin is complex, and there is skepticism about the effectiveness of this drug for some of its many off-label uses.

¹Alkhaili C, Tanev F, Alkhaili B, Lowenthal DT. Treatment of sexual disinhibition in dementia: case reports and review of the literature. *Am J Ther* 2004;11(3):231-5.

²Steinman MA, Bero LA, Chren MM, Landefeld CS. Narrative review: the

promotion of gabapentin: an analysis of internal industry documents. *Ann Intern Med* 2006;145(4):284-93.

Cholinesterase inhibitors

- Studies evaluating the effects of cholinesterase inhibitors on dementia-related ISB have had conflicting results.
- One case report suggested reduction of ISB with rivastigmine treatment.
- While several other reports describe the emergence of hypersexuality in patients taking donepezil (level III evidence)

¹Hagermeier N, Schier A, Robertson D. Role of cholinesterase inhibitor in the management of sexual aggression in an elderly demented woman. *J Am Geriatr Soc* 2003;51(6):836.

²Chenail Z. Donepezil and hypersexuality: a report of two cases. *Prim Psychiatry* 2003;10(7):78-9.

³La Cioia D, Camiciasso E. Inappropriate sexual behaviors associated with donepezil treatment: a case report. *J Clin Psychopharmacol* 2010;30(2):221-2.

H2 receptor blockers 400-1600 mg/d oral cimetidine (nightly or divided doses; eg, 400 mg twice daily)	Worsening cognition, dizziness, multiple drug-drug interactions
Beta-blockers 5-20 mg oral Pindolol twice daily 40-80 mg oral propranolol twice daily	Hypotension, fatigue, bradycardia, bronchospasm
Antifungals 100-200 mg ketoconazole once daily	Sedation, headache, rash, photosensitivity, gastrointestinal upset, pruritus, hepatotoxicity
Potassium sparing diuretics 12.5 mg spironolactone once daily	Hyperkalemia, gynecomastia, change in hair growth, upper gastrointestinal ulcers, agranulocytosis

Ethical and Legal Issues

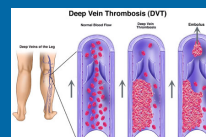
- Treatment: a conflict between an individual's autonomy and right to sexual expression.
- Whereas failure to treat may place the individual or others at risk for physical or mental harm.
- In the U.S. Resident Bill of Rights, federal regulations mandate that institutional care be as least restrictive as possible.

- Health care provider concerns about liability further complicate the treatment of hypersexuality in institutional settings.
- How do caregivers implement interventions, in the least restrictive means possible, while ensuring everyone's safety?
- Clear policies and procedures must be put in place for patients and staff regarding sexual behaviors
- Detailed assessments, effective interventions, and thorough documentation are the best mechanisms to prevent against liability suits in all care settings.

- Hormonal agents have been especially controversial.
- Stigmatized because of their use with the sex-offender population, critics refer to them as "chemical castration."



- Moreover, although these medications may be effective in reducing sexual behaviors, the drugs take weeks to act and increase the risks of venous thromboembolic disease and cardiovascular morbidity in residents of both genders



Final Discussion

- Hypersexuality is a real complex.
- Develop individualized interventions for hypersexual behavior. Comprehensive assessments using multiple data sources should be undertaken to determine contributors to hypersexual behaviors.
- **Always start with Non-Pharm:** such as privacy, redirection, use of male caregivers, and increased socialization.

Our Jobs:

A systematic policy and procedure approach is needed within each care institution focusing on hypersexual behaviors.

Training, Training and Training

Finally, staff can then plan individualized interventions so that hypersexuality can be more openly addressed.

Thank you

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