

Montefiore
THE UNIVERSITY HOSPITAL

 **EINSTEIN**
Albert Einstein College of Medicine
OF YESHIVA UNIVERSITY

Sex, Bioethics and Dementia

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Successful Aging

- (Your photo here)



Realistic View: Successful Aging

- Living Longer
- With Disability
- Success defined broadly enough to include wider range of older persons
- How do we flourish with disability as we age?
- How do we envision successful aging with dementia?

Dementia's Course

- 10 or more years duration, variable length
- Early phase: modest impairment
 - **Greatest number**
- End-stage: bed-bound, incontinent, loss of speech & swallowing, fatal outcome

- Many doctors don't diagnose until later phases
- Many people think only of final phase
- **Result: Poor support for long years before**

Lonni Schicker, EdD MHSA RN NIH Summit on Dementia Care

Development of a person-
centered that includes
individual preferences and
quality of life needs

How do we help people in early stages of dementia?

- Dementia gradually lowers decisional capacity
- Gradual shift in function, preferences
 - Gradual, individualized support from the start
 - Tailored to needs expressed by PwD
 - Accepting help can mean greater freedom, better quality of life

Bioethics and Dementia

- Balancing Autonomy and Beneficence
- Dementia attacks cognition, judgment, memory
- Emotion, need for intimacy may persist

- How do we protect the vulnerable, AND
- Support autonomy
 - Not just based on reason
 - Values and preferences

Sex and Dementia

- Sexuality: behaviors that define adulthood
- Inherent Risk
- Intensely personal, private
- Appealing BECAUSE dangerous
- Available in early stage (and later) dementia
- Challenge in weighing risks/benefits
- How to support without infantilizing?
- How to balance autonomy and beneficence?

Bias vs. Reality



- Bias that people w Dementia asexual
- Truth: wide variation of sexual interest, practice
- Home-dwelling partnered PwD:
 - 59% men, 51% women sexually active
 - 41% age 80-91
 - Ever discussed w Dr: 17% men, 1% women

- JAGS 2018 Oct Lindau et al

Case: Person with dementia as victim

- Henry Rayhons: 78 yo Iowa state legislator
- Donna Lou: 78 yo wife, develops dementia
- Henry arrested for having sex with wife in nursing home
- Lack of capacity to consent?

- Blended family: Donna's daughters' distress
- Nursing home without policy
- Sparks national conversation

Case: Person with dementia as aggressor

- Older woman caretaker of husband
- Confides to doctor :
 - husband has impaired judgment
 - Continued sexual desires
 - Sexual violence in home

- Rarely reported, discussed
- Likely to be common

“Inappropriate” Sexual Behavior in Dementia

- Inappropriate sexual behavior in community:
 - 18%, increased risk if male, anxiety
 - 2 million ppl x 18%: 360 K people
- 15% LTC staff report sexual aggression

- Am J Geri Psych 2017
- Geri Nursing 2017

Treatment of inappropriate sexual behavior

- No randomized trials, consensus documents
- Non-pharm intervention first
 - Change social cues
 - Distraction, activities
 - Restraints??
- Medication sparingly
 - Stop unhelpful meds, erectile dysfunction
 - Anti-depressants, SSRI

Appropriate sexual behavior in dementia?

- Sexuality reflects basic human identity/ need:
 - Intimacy
 - Touch,
 - Love, affection,
 - sexual behavior
- Sexual desire, activity continue in dementia

Sexual Consent and Dementia

- Consent capacity assessment
 - Non-judgmental, multi-disciplinary
 - Happens in some nursing homes
 - Rarely in community
 - Voluntary, non-transactional, individualized
 - Cannot be done in advance directive
 - Helps person with dementia who may need help rejecting sexual advances
 - Does not help caregiver without dementia who may need same help

What to do?

- Accept sexuality within disability, age
- Can be appropriate expression of affection, need for intimacy
- Differentiate sexuality from aggression
- Nursing home
 - Less privacy, more protection
 - Protection as rights infringement
- Community
 - More privacy, less protection

New Views on Sex and Dementia

- Rejecting old assumptions:
 - If PwD are asexual, then sexual behavior defined as deviant, risky
 - HCW must prevent/protect
- Proposing New Approach:
 - Duty to support right to benefit from and express sexuality
 - Autonomy not only found in reason, but in emotions, acts, expressed preferences
 - Gerontologist 2018

Sex and Dementia

- Focus on earlier phases of dementia
 - Early phase dementia includes participation in risky adult activities
 - Meeting PwD and Caregivers where they are, finding what they need, working together
 - Important to support autonomy
 - AND acknowledge vulnerability

How can we help patients, caregivers with dementia?

- Address stigma, fear
- Promote acceptance of aging WITH disability
- Shift to Care, not cure
- Quality of Life, Fullness of Life
- Wide range of supports
 - Drugs not best first approach
- Family, not just patient
- Community, not just family

Better caregiver support

- Overcome taboo on discussing sex
 - Not so easy!
- Home safety evaluation should include
- Medical evaluation should include
 - Assess partner concerns
- Urologist accountability for erectile dysfunction prescriptions
- Sexuality as part of life, health

Better way to see dementia

- Paradox of vulnerability:
- Accepting support means more independence
- 2 part burden of dementia
 - Actual symptoms of illness/disability
 - Societal burdens from stigma

Successful aging with dementia?

- Millions in coming decades
- Clear eyed view of approaching disability
- Requires societal shift in attitudes
- Less stigma, isolation
- Better planning, support for people with dementia and caregivers
- Greater freedom and safety in dementia
- Better quality of life

References

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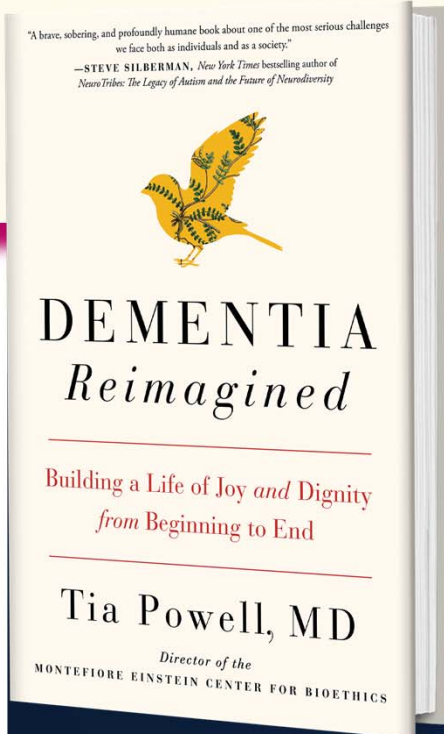


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Tia Powell, MD

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