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
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
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Tia Powell, MD
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