Sexuality in the Context of Dementia: Clinical Considerations and Challenges

Kelly O'Shea Carney, PhD, ABPP, CMC

Phoebe Ministries

Center for Excellence in Dementia Care

PHOEBE MINISTRIES

Program Objectives

- Establish understanding of disease processes and progression in Alzheimer's disease
- Explore aspects of healthy sexuality in older adults with dementia
- Enhance recognition of and response to indications of diminished capacity in relation to sexual activity
- Define interventions for managing unsafe or inappropriate sexual behavior in context of dementia

PHOEBE MINISTRIES

Neurocognitive Disorders
Progression and Insights from Research

PHOEBE MINISTRIES

Clarification of Terms

- Dementia: an umbrella term for cognitive change
- Neurocognitive disorder: the new diagnostic term for cognitive decline
- Alzheimer's disease: Most common cause of dementia
- Delirium: Abrupt change in mental status due to illness
- Memory loss: Most obvious symptom of Alzheimer's disease
- Confusion: A general symptom of later stage dementia

PHOEBE MINISTRIES

Neuro-cognitive Disorders

- Delirium
- Mild NCD
  - Probable Etiology Specification
- Major NCD
  - Alzheimer's Disease
  - Vascular Disease
  - Lewy Body Disease

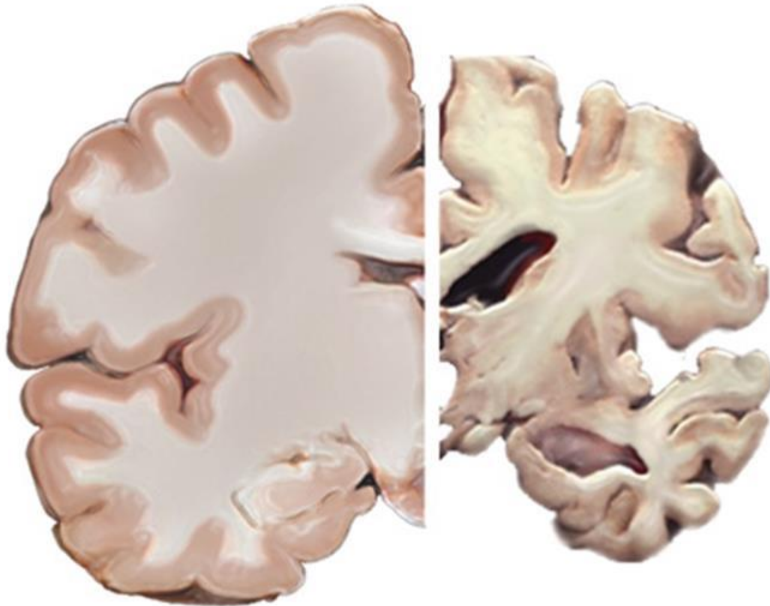
PHOEBE MINISTRIES

Most Common Etiologies

Diagnosis	Most obvious deficit
Alzheimer's disease	Memory loss and executive function
Vascular dementia	Loss of attention and motor function
Mixed etiology*	Memory, but with greater variability
Lewy Body Dementia	Psychiatric changes and motor loss
Frontotemporal Degenerations	Behavioral disinhibition and fluctuating mental status

PHOEBE MINISTRIES

Hallmarks of Alzheimer’s



- 60% to 80% of all dementia is due to AD
  - Perhaps more when considering mixed etiology
- Amyloid Plaques
- Neurofibrillary Tangles (Tau)
- Loss of connection between cells and regions

PHOEBE MINISTRIES

What Changes Happen in the Brain?

- Cellular
  - Amyloid plaques
  - Neurofibrillary tangles
- Chemical
  - Decreased acetylcholine
  - Dementia medications inhibit reuptake of acetylcholine
- Electrical
  - EEG evidence of slowed brain wave activity
  - Loss of connection between cells
- Neuroanatomical
  - Hippocampus
  - Amygdala
  - Temporal, parietal and prefrontal lobe disconnect
- Structural
  - Atrophy
  - Enlarged ventricles

PHOEBE MINISTRIES

A Summary of Disease Progression

Wh·t is Alzheimer's disease?

PHOEBE MINISTRIES

Emerging Perspectives on AD

- Prompted by ability to detect pathophysiological processes
- Expanded conceptualization of the disease spectrum and progression
- Recognition that underlying disease and clinically observable syndromes are not in complete correspondence
- Proposes a disease progression that moves from pre-clinical to late stage dementia
- Utilizes biomarkers within clinical criteria
- Increased focus on role of biomarkers in AD research

PHOEBE MINISTRIES

Abnormal

- Amyloid-β accumulation (CSF/PET)
- Synaptic dysfunction (FDG-PET/fMRI)
- Tau-mediated neuronal injury (CSF)
- Brain structure (volumetric MRI)
- Cognition
- Clinical function

Normal

Preclinical

MCI

Dementia

Clinical Disease Stage

Sperling, R.A. et al. Toward Defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroup. *Alzheimer's & Dementia* 1-13 (2011).

PHOEBE MINISTRIES

Hypothetical model of AD pathophysiological cascade

Age
Genetics

Cerebrovascular risk factors
Other age-related brain diseases

Amyloid-β
Accumulation

Synaptic Dysfunction
Glial Activation
Tangle Formation
Neuronal Death

Cognitive Decline

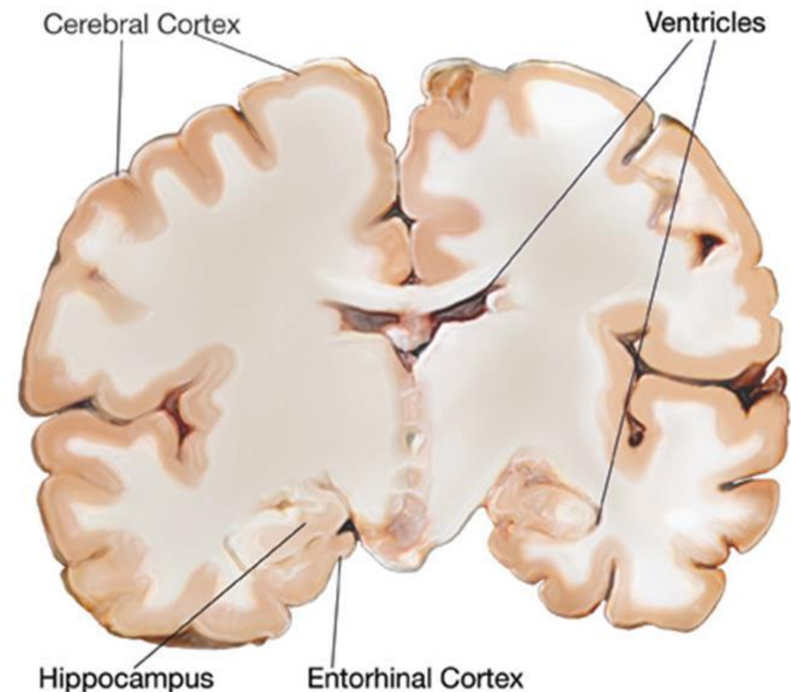
Brain and cognitive reserve
? Environmental factors

Sperling, R.A. et al. Toward Defining the preclinical stages of Alzheimer's disease: Recommendations from the Nationall Institute on Aging and the Alzheimer's Association workgroup. *Alzheimer's & Dementia* 1-13 (2011).

PHOEBE MINISTRIES

Preclinical Stage

- Groundwork for AD is likely laid decades before symptoms appear
- Stage in which pathophysiological findings are present, but observable syndromes are not
- Currently diagnosed for research trials only
- Goal is to identify people at possible risk of AD and explore progression and interventions
- This is the stage at which modifiable lifestyle factors may be most effective



PHOEBE MINISTRIES

Stage 1
Asymptomatic amyloidosis
-High PET amyloid tracer retention
-Low CSF $A\beta_{1\text{-}42}$

Stage 2
Amyloidosis + Neurodegeneration
-Neuronal dysfunction on FDG-PET/fMRI
-High CSF tau/p-tau
-Cortical thinning/Hippocampal atrophy on sMRI

Stage 3
Amyloidosis + Neurodegeneration + Subtle Cognitive Decline
-Evidence of subtle change from baseline level of cognition
-Poor performance on more challenging cognitive tests
-Does not yet meet criteria for MCI

MCI → AD dementia

Sperling, R.A. et al. Toward Defining the preclinical stages of Alzheimer's disease: Recommendations from the Nationall Institute on Aging and the Alzheimer's Association workgroup. *Alzheimer's & Dementia* 1-13 (2011).

PHOEBE MINISTRIES

Mild Cognitive Impairment

Signs include:

- Concern regarding a change in cognition
- Impairment noted by person or family in more than one cognitive function
- Preserved functional ability

- Only a portion with MCI convert to AD (modifiable lifestyle plays a role)
- Self report of individual is often an accurate indicator of change

PHOEBE MINISTRIES

Mild Alzheimer's Disease

Signs Include:

- Inability to encode new memories
- Subtle changes in language
- Difficulties with judgment and reason
- Likely to look more confused in response to changes in routine

- Possible to "hide" symptoms in casual interactions
- Increased assistance at home is generally required

PHOEBE MINISTRIES

Moderate Alzheimer's Disease

- Signs include
  - Loss of memory encoding and recall
  - Increasing confusion
  - Need for supervision and structure
  - Loss of higher order thinking and reason
  - Behavioral challenges
  - May see some retained ability in familiar activity

PHOEBE MINISTRIES

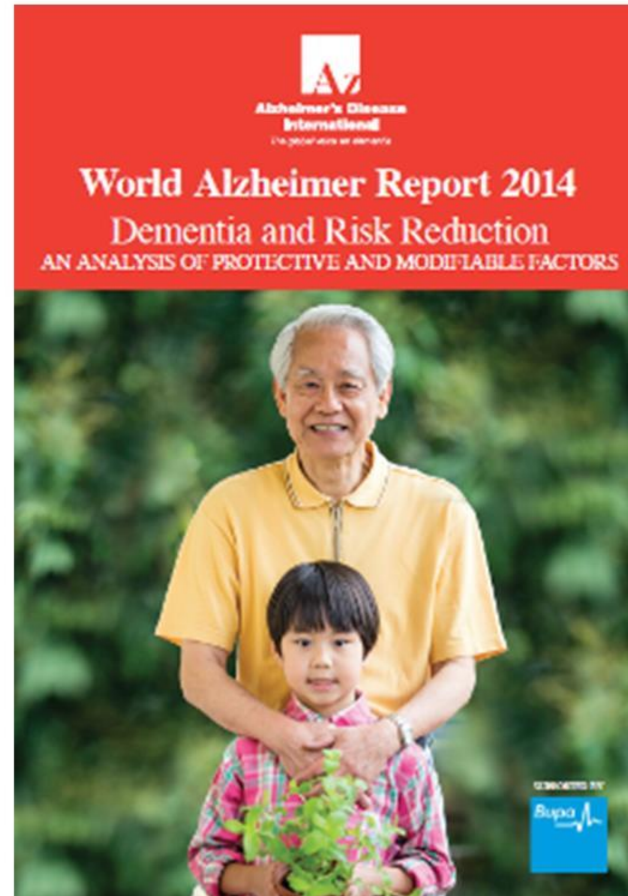
Severe Alzheimer's Disease

- Signs include:
  - Impairment in all areas of cognition
  - Complete dependence upon others for care
  - Limited ability to interact socially, but still responsive to touch and attention
  - Limited variation in signs and symptoms across etiologies

PHOEBE MINISTRIES

Potential Trajectory "Benders"

- Diet
- Exercise
- Cognitive stimulation
- Social connections
- Preventative medical care
- Stress management
  - Maintaining mood
  - Spiritual practices



PHOEBE MINISTRIES

Person Centered Care

"Overall, dementia care in this country is impersonal and fragmented, and this paper is a call to action to change to what is considered the gold standard — a person-centered approach."

PHOEBE MINISTRIES

The Take Home Message

DEMENTIA IS NOT A MONOLITHIC CONSTRUCT.

DIVERSITY, COMPLEXITY, CHANGEABILITY AND INDIVIDUAL UNIQUENESS **MODERATE THE PREDICTABLE ASPECTS OF THE DISEASE.**

THEREFORE, DIAGNOSIS ALONE CANNOT DETERMINE CARE DECISIONS

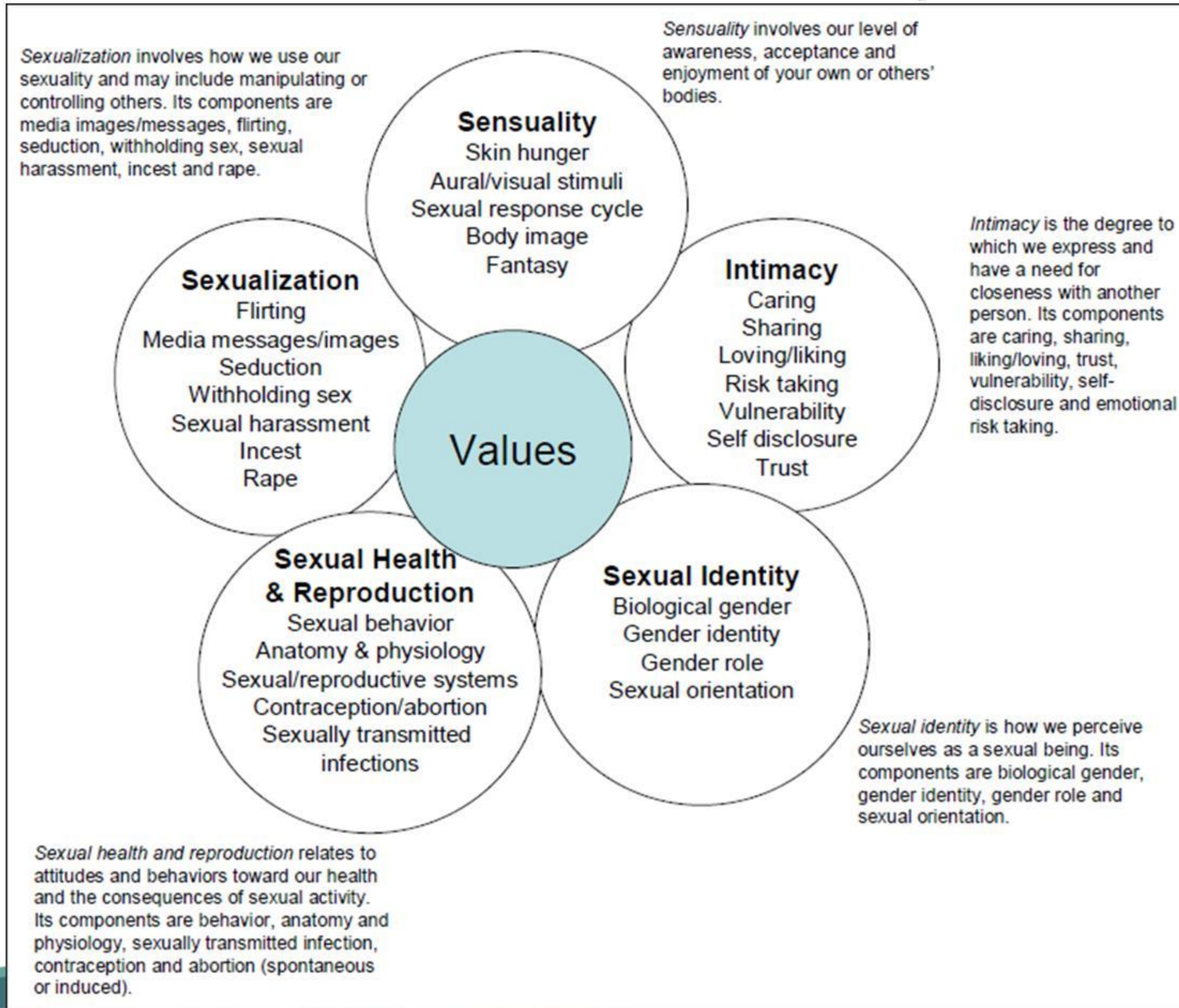
PHOEBE MINISTRIES

Healthy Sexuality and Aging

- Human sexual interactions are normal and natural
- Emotional and physical intimacy is important in the lives of many older adults
- The ability to engage is sexual activity is considered a human right
- The need for sexual expression and intimate relationships does not diminish with age

PHOEBE MINISTRIES

Circles of Sexuality



Dailey, D. (1981). Retrieved from:
http://www.health.state.mn.us/topics/sexualhealth/circlesofsexuality.pdf

Literature on Sexuality in Dementia

- Relatively understudied area of dementia care
- Available data suggests Inappropriate Sexual Behavior (ISB) is relatively rare compared to other behavioral challenges *
- Caregiver factors are of greatest importance in responding to ISB
  - Education
  - Attitudes
  - Assessment
  - Policies to guide response

PHOEBE MINISTRIES

*Tsatali, et. al. (2011). The Complex Nature of Inappropriate Sexual Behaviors in Patients with Dementia: Can We Put It Into a Frame? Sexual Disabilities, 29: 143-156.

Legal and Ethical Considerations

Legal

- Concern about survey deficiencies
- Concern about complaints and/or litigation by families
- Concern about implications for professional license

Ethical

- Clear duty protect vulnerable adults
- Yet, questions remain –
  - What is harm related to sexual activity?
  - Who should have the authority to make decisions regarding sexual activity?
  - What is criteria should be used to assess capacity in sexual decisions?
  - Recognizing unique nature of sexual activity and "dignity of risk"*

PHOEBE MINISTRIES

*Tarzia, L., Fetherstonhaugh, D. & Bauer, M. (2012). Dementia, Sexuality and Consent in Residential Aged Care Facilities. Journal of Medical Ethics, 38, 609-613.

Sexuality in Long Term Care Settings

- Complex challenge of managing the balance between duty to care and unnecessarily limiting individual rights
- Resources necessary to manage the complications
  - Philosophy and policy
  - Staff training
  - Systems and resources for determining capacity
  - Systems and resources for responding to issues of diminished capacity
- Hebrew Home in River Spring, NY as a leader in supporting the right to sexual expression for older adults
  - Policy and guidelines established in 1985

PHOEBE MINISTRIES

To view the Hebrew Home policy, go to:
http://www.riverspringhealth.org/sexual-expression-policy.aspx

Framework for Resident Rights

- Residents have the right to engage in mutually consensual sexual activity, excluding:
- Non-consensual acts – understanding that "consent" requires capacity
- Acts with minors
- Acts between persons if there is any possibility of the transmission of an STD
- Acts that impact negatively on the resident community as a whole through public display
- Illegal acts

PHOEBE MINISTRIES

Hebrew Home at Riverdale (2013). Policies and Procedures Concerning Sexual Expression at the Hebrew Home at Riverdale. Retrieved at: http://www.riverspringhealth.org/files/sexualexpressionpolicy.pdf

Support for Healthy Sexual Expression

- Support and place no unreasonable constraints on the intimate relationships of residents
- Support and place no unreasonable constraints on the sexual activities of residents.
- Provide both anticipatory and situational supports for the intimate relationships and sexual activities of residents.
- Provide appropriate risk-related health information pertaining intimate relationships and sexual activities to residents and their healthcare surrogates.

Center for Practical Bioethics (2006). Considerations Regarding the Needs of Long-Term Care Residents for Intimate Relationships and Sexual Activity. Retrieved at: https://www.practicalbioethics.org/files/guidelines/Intimacy_Guidelines_Aug2007.pdf

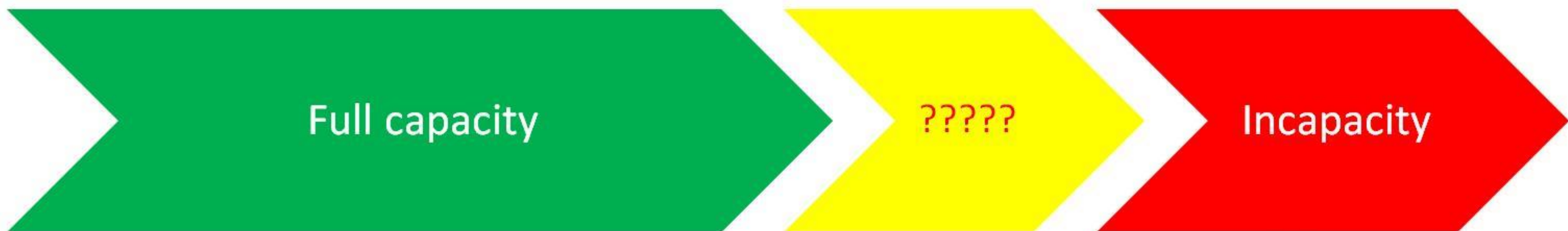
PHOEBE MINISTRIES

Simple Strategies to Support Healthy Sexual Expression

- Ongoing support and education is provided to staff
  - Recognition that positive attitudes are as important as knowledge and skills
- Do Not Disturb signs available for use by residents
- Train staff to knock before entering resident rooms
- Sexual health education resources are available to residents, family members and significant others
- Acknowledge and address sexual needs and issues via care planning, as appropriate
- Availability of common items necessary for safe sex
  - e.g. condoms, personal lubricant, etc.
- Access to adaptive devices and supports, if needed

PHOEBE MINISTRIES

When Questions Arise: Progression and Capacity



PHOEBE MINISTRIES

Healthy Sexual Expression and Disease Progression

- How do we determine what behaviors are safe and appropriate in the context of diminishing capacity?
- Principles of Person Centered Care guide us
  - What are the individual's values?
  - What behaviors were typical before their illness?
  - What is the nature of the behavior?
  - What is the relationship within which the behaviors are occurring?
  - What does the resident tell us about their preferences, views and choices in the matter?

PHOEBE MINISTRIES

Examples to Consider

- How do we feel about….
- Hand holding with a new partner in the context of moderate dementia?
- Sexual intercourse with a spouse in the context of mild dementia?
- Cuddling in bed with a long term partner in late stage dementia?
- Sexual intercourse with a spouse in the context of later stage dementia?
- *Answers are seldom clear cut or easy….*

PHOEBE MINISTRIES

Understanding Capacity

- Legal presumption of capacity exists unless adjudicated as incapacitated.
- Capacity is considered an issue specific construct
  - Not an “all or none” determination
  - Transaction specific legal standard vary from State to State.
- Legal capacity to consent to sexual activity is based on law related to criminal prosecutions for sex with incapacitated person and requires:
  - Knowledge of facts related to decision
  - Capacity to understand and process risks and benefits
  - Voluntariness, i.e. absence of coercion

PHOEBE MINISTRIES

Clinical vs. Legal Capacity

Clinical

- Clinical assessment required to determine legal capacity
- Function is viewed as a continuum with focus on relative strengths
- Clinical determinations take into account cognitive ability, along with function, emotion, context and resources

Legal

- Assessment informs, but does not determine legal capacity
- Transaction specific capacity is viewed as a binary construct (Yes or No)
- Legal standards based on simple template
  - Can the individual understand and perform the essential functions for the transaction?

PHOEBE MINISTRIES

American Bar Association/American Psychological Association (2008). Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists. Retrieved at: http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf

Capacity Determination

Clinical Judgment

Functional Elements

Diagnosis

Cognitive Underpinnings

Psychiatric and Emotional Factors

Values and Preferences

Risk Considerations

Steps to Enhance Capacity

Legal Standard

PHOEBE MINISTRIES

American Bar Association/American Psychological Association (2008). Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists. Retrieved at: http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf

Complications in Applying Capacity Standards

- The legal standard sets a solid foundation from which to consider issues
- *But what about where no legal violation exists?*
- *What is the proper standard for capacity related to decision making regarding sexual activity?*
- Consider what standards you use to guide these decisions in your own life….

PHOEBE MINISTRIES

Unique Aspects of Sexual Consent

- Unlikely to have opportunity to seek guidance regarding potential costs/benefits from others
- Decisions related to sexual behavior tend to be more spontaneous
- Surrogate decision maker cannot be appointed for making sexual decisions
- In these regards, capacity to consent to sexual relations is different from other capacity related transactions

PHOEBE MINISTRIES

Perspectives on Consent to Sexual Activity

Required by Law

- Knowledge
  - Ability to understand the act, the relationship and the possible implications of the act
- Understanding of Risks and Benefits
  - Can recognize and process the physical, emotional and relationship related risks/benefits
- Voluntariness
  - Ability to avoid coercion and set limits on activity

Recommended for Consideration

- Nature and extent of the risks
- Nature and extent of the sexual behavior
- Environmental and relationship context for the behavior
- Values, history and preferences of the individual

PHOEBE MINISTRIES

Questions to Begin Assessment of Sexual Consent Capacity

- Patient's awareness of the relationship
  - Can they say who the partner is? What is their relationship? Can nature of relationship be described?
- Patient's ability to avoid exploitation
  - Is behavior consistent with former beliefs and values? Can patient say no to unwanted advances?
- Patient's awareness of potential risks
  - Does patient realize limitations of relationship? Can patient describe any potential harm to self or others that may occur?

Lichtenberg, P. & Strzepek, D. (1990). Assessments of Institutionalized Dementia Patient's Competencies to Participate in Sexual Relationships. The Gerontologist, 30 (1), 117-120

Resources Necessary to Assess Capacity

- Geropsychologist or Neuropsychologist
- Psychiatrist or Geriatrician
- Handbook for Assessing Diminished Capacity
  - ABA/APA (2008)
- Facility philosophy and policy
- Staff training
- No standardized tools are currently available
  - Comprehensive assessment and good clinical judgment are required
- Review by interdisciplinary team

PHOEBE MINISTRIES

Important Clarifications…

Sexual activity generally diminishes with advancing dementia

Inappropriate sexual activity among individuals with dementia is relatively rare

Often it is not the behavior that is inappropriate, rather the context in which it occurs that is inappropriate

PHOEBE MINISTRIES

Clear Incapacitation

- When clinical assessment determines incapacitation and/or legal determination is made…
- Facility has a clear responsibility to monitor and manage sexual behavior in conjunction with family and/or surrogate decision maker
- Safety considerations and person centered principles guide decision making

PHOEBE MINISTRIES

The Devil is in the Details…

- Context and person centered assessment must drive clinical decision making
- Detailed documentation of concern will provide situational context
  - Consider use of ABC model to document behaviors
- Analysis of issues at hand should rely on person centered assessment to provide unique context for the individual

PHOEBE MINISTRIES

Indication for Intervention

- Sexual behavior poses a risk to individual or others
- Non-consensual sexual activity
- Inappropriate sexual behavior, characterized by act in a context that is not considered socially acceptable
  - Sex talk
  - Sexual acts
  - Implied sexual acts

PHOEBE MINISTRIES

Intervention Options

- Monitor and support appropriate activity
- Behavior management to reduce challenging behavior and encourage desirable behavior
- Medication
  - Last resort only
  - Always in combination with behavioral and non-pharmacologic interventions

PHOEBE MINISTRIES

Monitor and Support

- Identify the underlying need and offer alternatives to address that need
- “Iatrogenic loneliness” – Higgins (2004)
- Provide opportunities to meet needs via appropriate channels
  - Socialization
  - Affection
  - Tactile stimulation
  - Privacy for self stimulation
  - Movement and exercise
  - Aromatherapy

PHOEBE MINISTRIES

Gastmans, C. (2014). Sexual Expression in Nursing Homes: A Neglected Nursing Ethics Issue. Nursing Ethics, 21 (5), 505-506.

Behavior Management Process

- Observe and document behavior
- Analyze observation in context of life story, medical history and current circumstances
- Identify triggers and consequences that promote and support behavioral expressions
- Develop a plan to alter triggers and consequences, while meeting underlying needs
- Monitor, review and revise plan as needed

PHOEBE MINISTRIES

Taxonomy for Documentation

- Characteristics of individual: Demographics, medical concerns, changes in status
- Antecedents: Environmental and interpersonal triggers to behavior
- Behaviors: Target person, type of behavior, environmental context (when, where)
- Consequences: Characteristics of caregiver responding, description of response, resident's reaction to response

PHOEBE MINISTRIES

Makimoto, et. al. (2015). Integrated literature review on sexuality of elderly nursing home residents with dementia. International Journal of Nursing Practice, 21, 80-90.

Behavior Management Applied

- Alter environment and routine
  - Provide privacy for self stimulation
  - Ensure activity and diversion in public spaces
  - Offer aromatherapy and music to calm and soothe
- Reduce triggers to behavior
  - Assign staff that are less likely to be misinterpreted
  - Alter shows on TV
  - Consider effect of words and routine in relation to life history

PHOEBE MINISTRIES

Behavior Management Applied

- Encourage desirable behavior
  - Offer gentle touch and affection
  - Provide grooming to enhance confidence
  - Engage in genuine relationship with residents
    - Laughter, sharing, joking, hugs
- Manage responses to behavior
  - Train staff to respond firmly and clearly to behaviors
  - Acknowledge and encourage appropriate affection, touch and socialization

PHOEBE MINISTRIES

Medications

- Intervention of last resort
  - Limited efficacy
- Always in combination with behavioral interventions
  - Person centered care vs. medical approach
- Medication options may include:
  - Hormones
  - Anti-depressants
  - Cholinesterase inhibitors

In Sum….

- The topic is often uncomfortable and unfamiliar
- The issues are complex
- Assessment must be multi-faceted and grounded in respect for person and their uniqueness
- Responses should be sensitive and supportive while maintaining safety
- Staff education and attitudes are key to success in addressing these issues
- Clear policies and processes provide structure to navigating complexity and sensitivity of issues

PHOEBE MINISTRIES

For more information, please contact:

Kelly O'Shea Carney, Ph.D., ABPP, CMC
Center for Excellence in Dementia Care
Phoebe Ministries
Allentown, PA
610-794-MIND
kcarney@phoebe.org
www.phoebe.org/cedc

PHOEBE MINISTRIES

Selected References

American Bar Association Commission on Law and Aging & American Psychological Association. (2008). Assessment of older adults with diminished capacity: A handbook for psychologists. Washington, DC: American Bar Association Commission on Law and Aging/American Psychological Association.

American Bar Association/American Psychological Association (2008). Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists. Retrieved at:
http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf

Archibald, C. (2002). Sexuality and dementia in residential care – whose responsibility? Sexual and Relationship Therapy, Vol 17, No. 3, 2002.

Bardell, A., Lau, T. and Fedoroff, J.P. (2011). Inappropriate sexual behaviour in a geriatric population. International Psychogeriatrics, 23(7), 1182 – 1188.

Bauer, M., McAuliffe, L., & Nay, R. (2007). Sexuality, health care and the older person: An overview of the literature. International Journal of Older People Nursing, 2(1), 63-68.

Bauer, M. McAuliffe, L., Nay.R., Chenco, C. (2013). Sexuality in Older Adults: Effect on an Education Intervention Attitudes and Beliefs of Residential Aged Care Staff. Educational Gerontology, 39, 82-91.

PHOEBE MINISTRIES

Selected References

Center for Practical Bioethics (2006). Considerations Regarding the Needs of Long-Term Care Residents for Intimate Relationships and Sexual Activity. Retrieved at:
https://www.practicalbioethics.org/files/guidelines/Intimacy_Guidelines_Aug2007.pdf

Dailey, D. (1981). Retrieved from: http://www.health.state.mn.us/topics/sexualhealth/circlesofsexuality.pdf

Dementia Initiative 2013

Gastmans, C. (2014). Sexual Expression in Nursing Homes: A Neglected Nursing Ethics Issue. Nursing Ethics, 21 (5), 505-506.

Hebrew Home at Riverdale. (2013). Policies and Procedures Concerning sexual expressions at the Hebrew Home at Riverdale. Retrieved at: http://www.riverspringhealth.org/sexual-expression-policy.aspx

Horowitz, A.C. (2015). Sexual intimacy and dementia: The tricky business of sexual consent in SNFs. Long Term Living, July August.

Lichtenberg, P. & Strzepek, D. (1990). Assessments of Institutionalized Dementia Patient's Competencies to Participate in Sexual Relationships. The Gerontologist, 30 (1), 117-120

Makimoto, et. al. (2015). Integrated literature review on sexuality of elderly nursing home residents with dementia. International Journal of Nursing Practice, 21, 80-90.

PHOEBE MINISTRIES

Selected References

Sperling, R.A. et al. (2011). Toward Defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroup. Alzheimer's & Dementia 1-13.

Stubbs, B., (2011). Displays of inappropriate sexual behavior by patients with progressive cognitive impairment: the forgotten form of challenging behavior? Journal of Psychiatric and Mental Health Nursing, 18(7), 602–607.

Syme, M, Cordes, C., Cameron, R., and Mona, L. (2014). Sexual Health and Well Being in the Context of Aging. In P. A. Lichtenburg and B. T. Mast (Eds.), American Psychological Association Handbook of Clinical Geropsychology. Washington, DC: APA Press.

Tarzia, L., Fetherstonhaugh, D. & Bauer, M. (2012). Dementia, Sexuality and Consent in Residential Aged Care Facilities. Journal of Medical Ethics, 38, 609-613.

The Last Taboo – a guide to dementia, sexuality, intimacy and sexual behaviours in care homes. Retrieved from: www.ilcwk.org.uk

Tsatali, M., Tsolaki, M, Christoloulou, V., and Papliagkas, V. (2011). The Complex Nature of Inappropriate Sexual Behaviors in Patients with Dementia: Can We put it into a Frame? Sexuality and Disability 29(2), 143-156.

Weinberg Center and The Hebrew Home at Riverdale. Assessing Consent to Sexual Activity in Older Adults.

PHOEBE MINISTRIES