VETERANS HEALTH ADMINISTRATION

Intimacy and Dementia

Presentation for: GRECC-Connect Case Conference Series
Presented by: Megan E. Gately, PhD, OTR/L
Date: March 10, 2023

RURAL VETERAN VISION, MISSION & STRATEGIC GOALS

VISION

America's Veterans thrive in rural communities

MISSION

Improve the health and well-being of rural Veterans through research, innovation, and the dissemination of best practices

Promote federal and community care solutions for rural Veterans

OBJECTIVES

- Unite relationships within VA and the federal government to exchange rural-centered information
- Collaborate with non-governmental organization that support rural Veterans' health and well-being
- Expand ORH's partnership and programing reach

Reduce rural health care workforce disparities

OBJECTIVES

- Expand understanding of current health care workforce
- Support rural implications of the MISSION Act

Enrich rural Veteran health research and innovation

OBJECTIVES

- Increase rural Veteran health research
- Innovate new models of care for Veterans who live in rural communities
- Build recognition of VA's rural research, innovations and outcomes

ORH Resources Related to Intimacy and Dementia

Caregivers Video Series, "Intimacy and Dementia" (7 min video), https://www.ruralhealth.va.gov/vets/intimacy.asp

Dementia Resources for Caregivers and Families (website), https://www.gerischolars.org/course/view.php?id=41

Objectives

1. describe the impact of dementia on Veteran sexual expression;
2. define intimacy as it relates to sexual functioning and dementia;
3. identify at least 2 strategies to address Veteran with dementia's need for sexuality and intimacy, including the importance of partnering with caregivers.

Case

- 85 y.o. Veteran with brain injury >10 yrs ago, increasing cognitive impairment since then, now demented and unable to manage own affairs. Lives with wife. They have not been sexually active for over a decade. For past few months he has been importuning her to have sex several times a week and sometimes several times a day, including acts she would never agree to. He is not violent or aggressive but he is persistent.

- Margot and Wally have been married for 45 years. Throughout that time, they were very comfortable in their bodies and had a sexually satisfying relationship, including into older adulthood. Now that Wally has been diagnosed with dementia, Margot has taken on more responsibility for his day-to-day needs. She now describes their relationship as being “like living with a very pleasant eight year old.”

Sexuality

- A central aspect of being human throughout life; encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction
    - WHO, 2006
- Incorporates physical, emotional, cognitive, and social aspects; reflects one's beliefs

(Mis)perceptions about sex

- Sex is only for young, male, able-bodied individual
- Sex is only for married or partnered individuals
- Sex is dangerous for individuals with health conditions and/or older adults
- Other health care professionals (“not it”) will address sex
- Sex = intercourse
- Sex is a private activity, and should not be discussed publicly
- Sex is for reproduction
- Sex is not as important as other occupations

Sexuality and aging

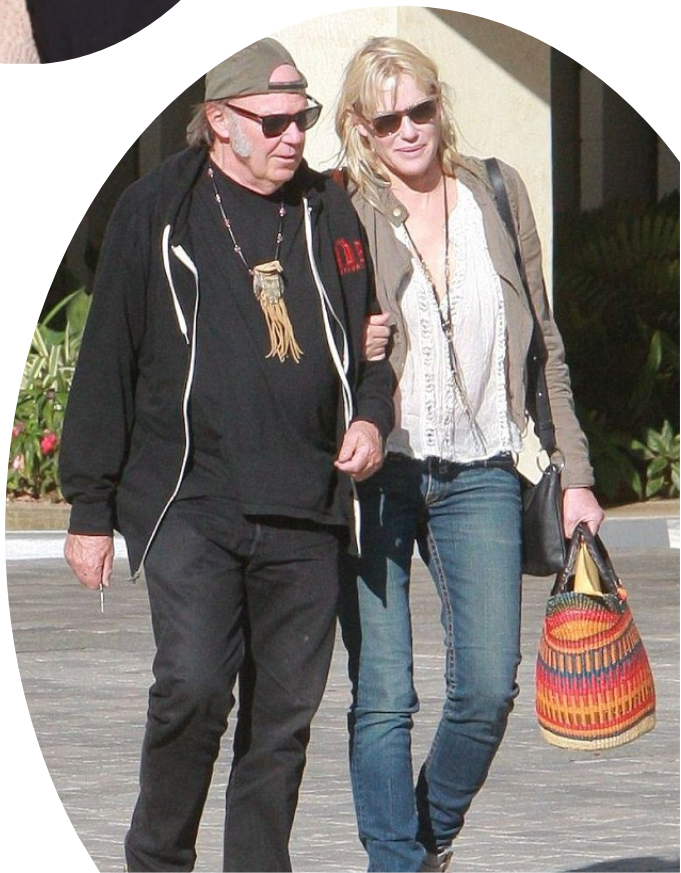
- Fluid construct
- Aging may allow for different/renewed sexual interest (retirement, divorce, financial solvency)
- Sexual activity continues for many into 80s, despite sex-related dysfunction
    - Erectile dysfunction, decreased lubrication most common problems
- Satisfaction with sex associated with overall health and wellness

Lindau et al, 2007

- Perspectives about and patterns of sex vary by race, gender, ethnicity, and cultural background

Baby Boomers

- Born between 1946-1964 (aged 59-77)
- “Make Love Not War”
- Second sexual revolution
- Believe that sexual dysfunction needs to be treated
- They are not willing to exclude sexual needs as part of growing older
- They feel sex is ageless



PLISSIT

- Permission
  - Provide a relaxed, nonjudgmental environment that gives the client permission to discuss any issues or concerns
- Limited Information
  - Provide specific, factual information on an one-to-one basis; dispel myths and misconceptions, particularly about disabilities
- Specific Suggestions
  - Provide strategies such as positioning or adaptive equipment to address specific problems
- Intensive Therapy
  - Provide long-term treatment for chronic sexual problems

- Robnett & Chop, 2018

Barriers to fulfilling sex life as older adult?

Barriers to fulfilling sex life as older adult

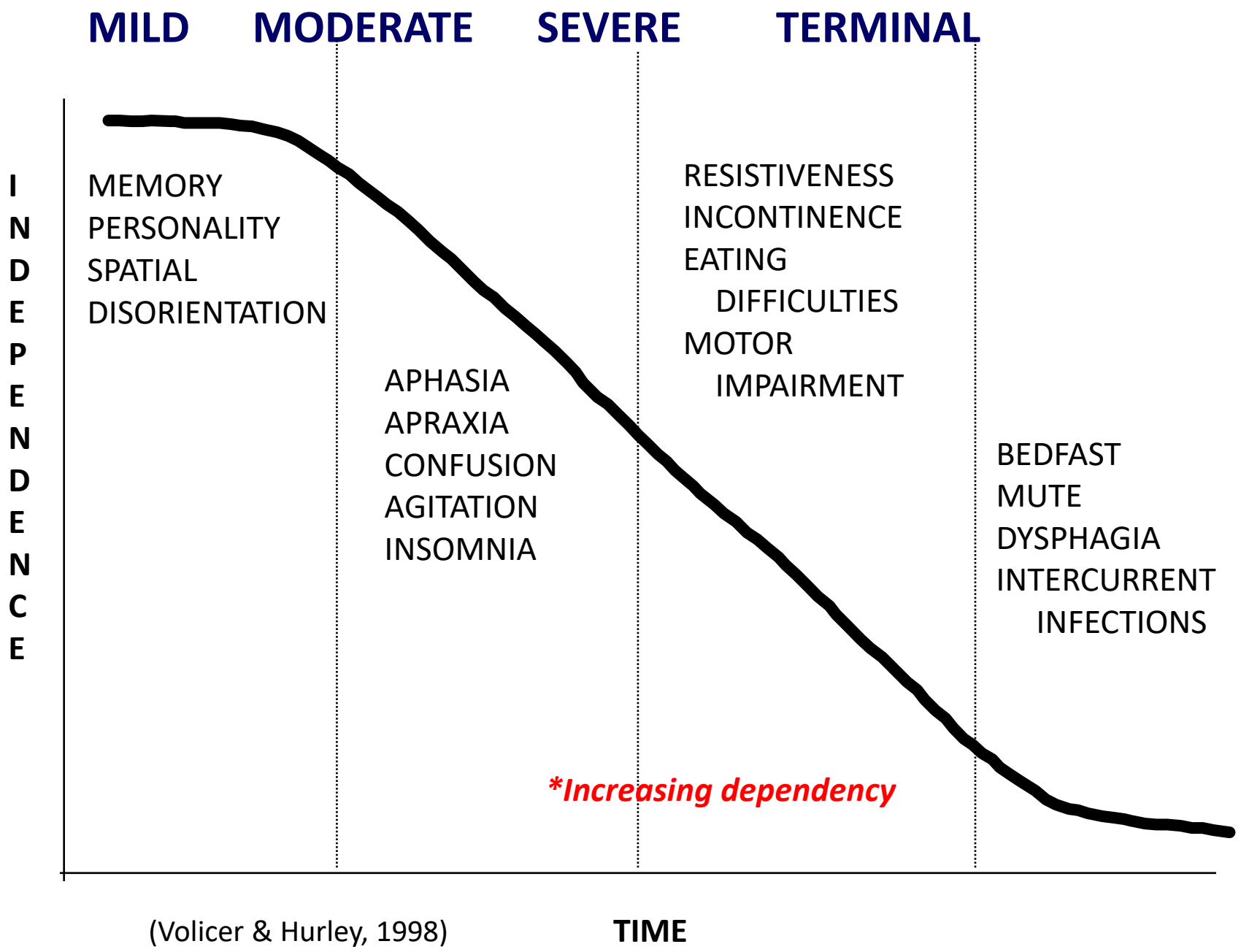
- Age-related changes or side effects of health conditions
  - Endurance
  - Pain, stiff joints, decreased ROM
  - Contractures
  - Tremors
  - Spasticity
  - Bladder or bowel dysfunction, incontinence
  - Muscle weakness
  - Sensation difficulties
- Lack of a partner
- Drug-related sexual dysfunction
- Psychosocial factors
- Clinician-client interaction
- *Cognitive impairment

Aging and cognitive impairment

- Aging or cognitive impairment does not take away the need for
  - Sexual expression
  - Affection
  - Intimacy
  - Relationships
  - Warmth
  - Touch

Intimacy

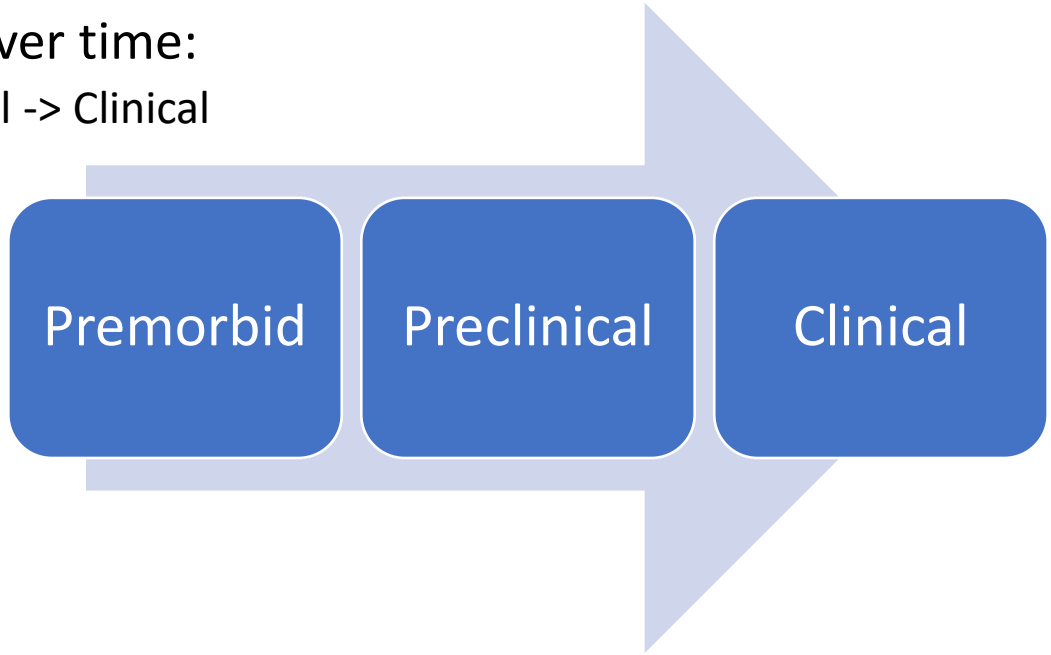
- The state of being personally intimate; intimate friendship or acquaintance; familiar intercourse; close familiarity; an instance of this
- Euphem. for sexual intercourse



(Volicer & Hurley, 1998)

Dementia and Sex: Renegotiation

- Over time/disease course, sex is renegotiated
- Starts off just the couple
- Increasing non-partner influences (family, clinicians) who take a mostly negative view
- See “Common” story over time:
  - Premorbid -> Preclinical -> Clinical



Claes & Enzlin, 2023

Premorbid: “Normal” aging couple

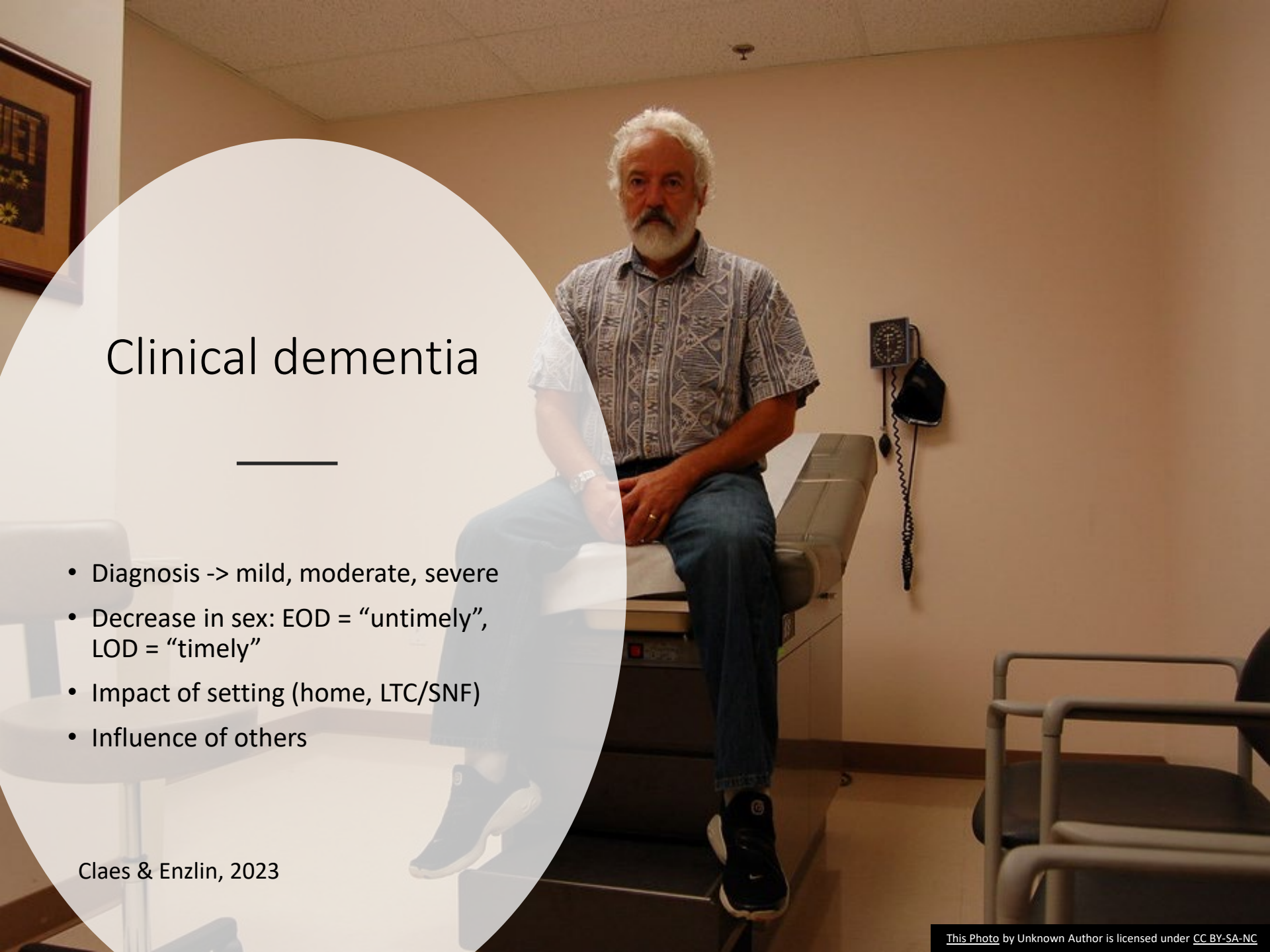
Claes & Enzlin, 2023

- Only players the two partners
  - attitudes, history, closeness, age-related changes/challenges
- Quality at this stage (satisfaction) may influence post-dx relationship
- More affection before = maintain affection after

Preclinical (before dementia diagnosis)

- First symptoms occur
  - Memory loss, apathy, agitation, disinhibition, agitation, personality changes, neuropsychiatric symptoms, irritability, decreased emotional control
- Uncertainty, depression/anxiety stress
- Changes to sexual relationships, but partners may not understand why
- May result in decline in sexual activity

Claes & Enzlin, 2023



Clinical dementia

- Diagnosis -> mild, moderate, severe
- Decrease in sex: EOD = “untimely”, LOD = “timely”
- Impact of setting (home, LTC/SNF)
- Influence of others

Claes & Enzlin, 2023

Person with dementia perspective

- Negative beliefs about dementia (self or other), body image
- Forgetting already had sex or age-related changes that affect sex (erectile dysfunction, arthritis, physical limitations, etc.)
- Requests for acts not normally performed, trouble inhibiting
- Decreased attention/ concentration
- *Decreased interest/apathy, depression
- May continue to be sexually active (May depend on whether partnered), sex as obligation, decreased pleasure
- Rates vary, but if active, satisfaction high

Claes & Enzlin, 2023; Digiorgio & Series, 2016

Partner perspective

Most couples report change in emotional quality of relationship, less sexual over time

Shift in roles; parent-child dynamic, not recognize partner as partner ("sexual grief")

Concern about consent, ethics

Shift from penetrative sex to touch, which can be more or less sexual in nature (maintain connection as couple)

Family perspective

- Increased control over the sex life of the person with dementia and partner
- May support intimacy (cuddling, kissing) but not endorse intercourse
- Concerns over ethics (safety, protective paradigm)
- Wishes often prioritized over person

Care team

- Ideal: Holistic care that includes sexuality of person
- May consider inappropriate, not a priority, not relevant, not recognize importance
- Need education and training to address sex
- Integrate into routine assessment, as couples likely will not raise but may need support
- Create safe and supportive environments to express sexuality in long-term care settings

“Hypersexual”/ Inappropriate Sexual Behavior (ISB)

- Sexually disinhibited behavior, or hyper-sexuality
- May depend on dementia type (AD = apathy, FTD/vascular = hypersexuality)
- Increased interest in sex, sex talk (language not in keeping with the premorbid personality), or acts (e.g., touching, grabbing, exposing, or masturbating, which can occur in private/public)
- ISB: “A specific sexual behavior marked by apparent loss of control or intimacy-seeking **misplaced in the social context or directed towards the wrong target**; behavior may be not sexual in its form but **in its suggestion**”
- Difficulty in interpretation and context; ***who decides?***
- **“Sexual agency… capacity to choose, engage in, or refuse sex acts and others recognize and respect one’s sexual identity”—is mostly not acknowledged”** especially in LTC settings
  - Claes & Enzlin, 2023: De Giorgi & Series, 2016

BEHAVIOR

=

COMMUNICATION

PLST Model

Progressively Lowered Stress Threshold

Types of behavior observed:

1. Baseline Behavior
2. Increasingly Anxious Behavior
3. Dysfunctional Behavior

Disordered person-environment interaction

Accumulation of stressors throughout each day

Decreased threshold for stress as disease progresses

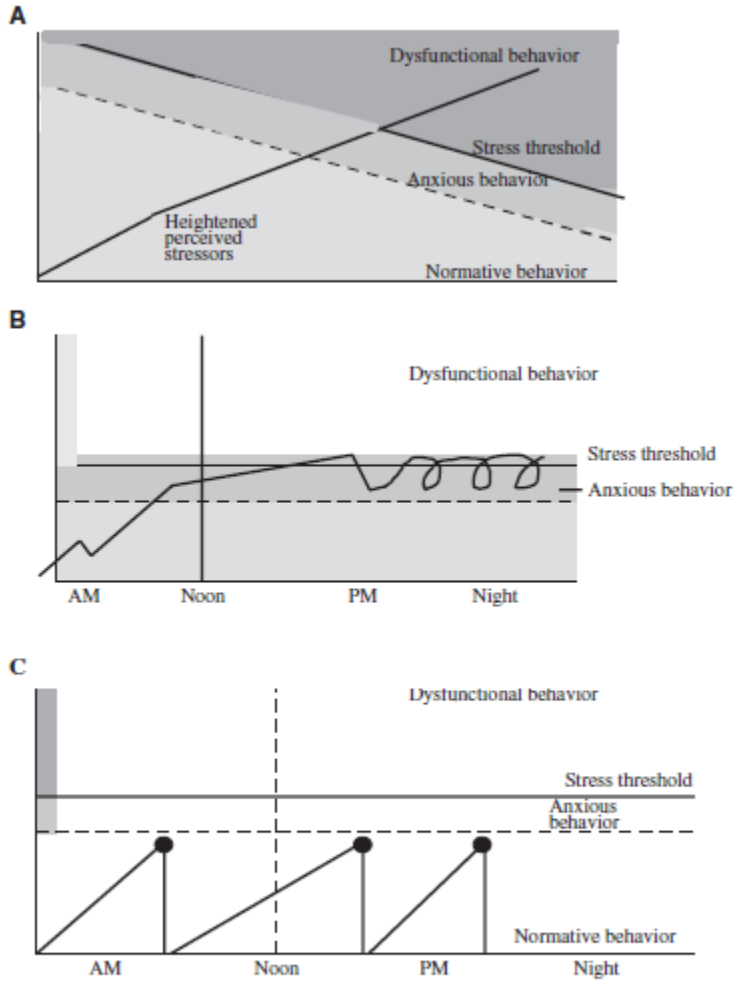


Fig. 1. A. Stress threshold in a patient with Alzheimer's disease and related disorders (ADRD). B. Effects of stress during a 24-hour day in a patient with ADRD. C. Planned activity levels for the person with ADRD.

(*Smith, Gerdner, Hall, & Buckwalter, 2004, p. 1756)*

Contributors to stress, according to PLST model

- Physical stressors (pain, discomfort, infection, fatigue)
- Misleading stimuli or inappropriate stimuli (*Bathing, dressing—how might that trigger sexual thoughts/response?)*
- Change of environment, caregiver, or routine (*Unfamiliar person providing personal care—how might that lead to confusion over relationship/expectation?)*
- Internal or external demand that exceeds functional capacity (*Inability to filter out environmental stimuli contributing to aggression or acting out)*
- ***May result in behavior that looks like "Inappropriate sexual behavior"***
  - *Hall et al, 1995*

Management of inappropriate sexual behavior

- *LACK of adequate clinical guidelines to address (biggest barrier to effective management)
- Non-pharmacological strategies
  - SHOULD be first line of defense
- Pharmacological strategies
  - Often first/only management strategy due to
    - Ease of administration
    - Perceived efficacy
    - Lack of staff training
- Low-level evidence for use of antidepressants, antipsychotics, anticonvulsants, cholinesterase inhibitors, hormonal agents, and beta-blockers
- Start at low dose and titrate up slowly and carefully

- *De Giorgi & Series, 2016*

Non-pharmacological strategies

- Environmental
- Behavioral (or cognitive-behavioral)
- Educational
- Involve patients, families and nursing staff for institutionalized subjects
- **Goal: Promote an "appropriate manifestation of sexual behavior rather than an eradication of it"**

• *De Giorgi & Series, 2016*

Environmental approaches

- Minimize confusing stimuli
  - Switch care staff gender if disorienting
- Avoid overstimulating television or radio programs or magazines
- Separate beds?
  - May heighten need for surveillance (e.g., door sensors, room monitors), in case of wandering

- *De Giorgi & Series, 2016*

Environment (continued)

- In CLC/nursing home, single rooms and conjugal visits may reduce the frequency of ISB by satisfying patient's sexual drive
- Increase way-finding to resident's room to prevent behavior that could be misconstrued as "inappropriate"

Behavioral approaches

- Exclude underlying causes, e.g., of undressing in public
  - Is the person hot? In pain? Needing to go to the bathroom?
  - Thinking it is bed-time?
- Re-direct or distract (may be physical or verbal)
  - Move to a private area
  - Provide structured and meaningful activity
  - Snacks, games, exercise, crafts, etc., to satisfy occupational needs
  - Active not passive; TV watching is NOT meeting occupational needs!

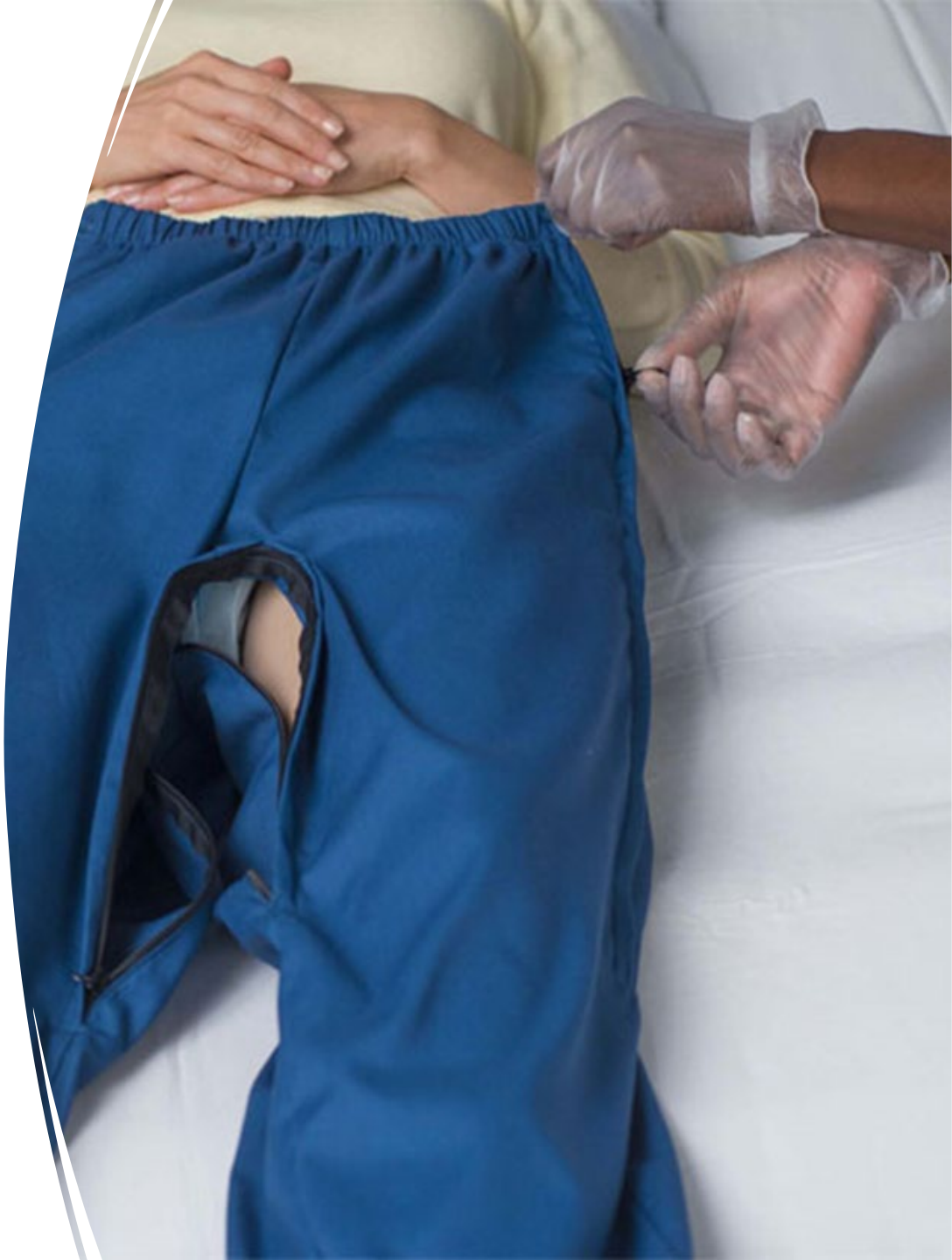
- *De Giorgi & Series, 2016*

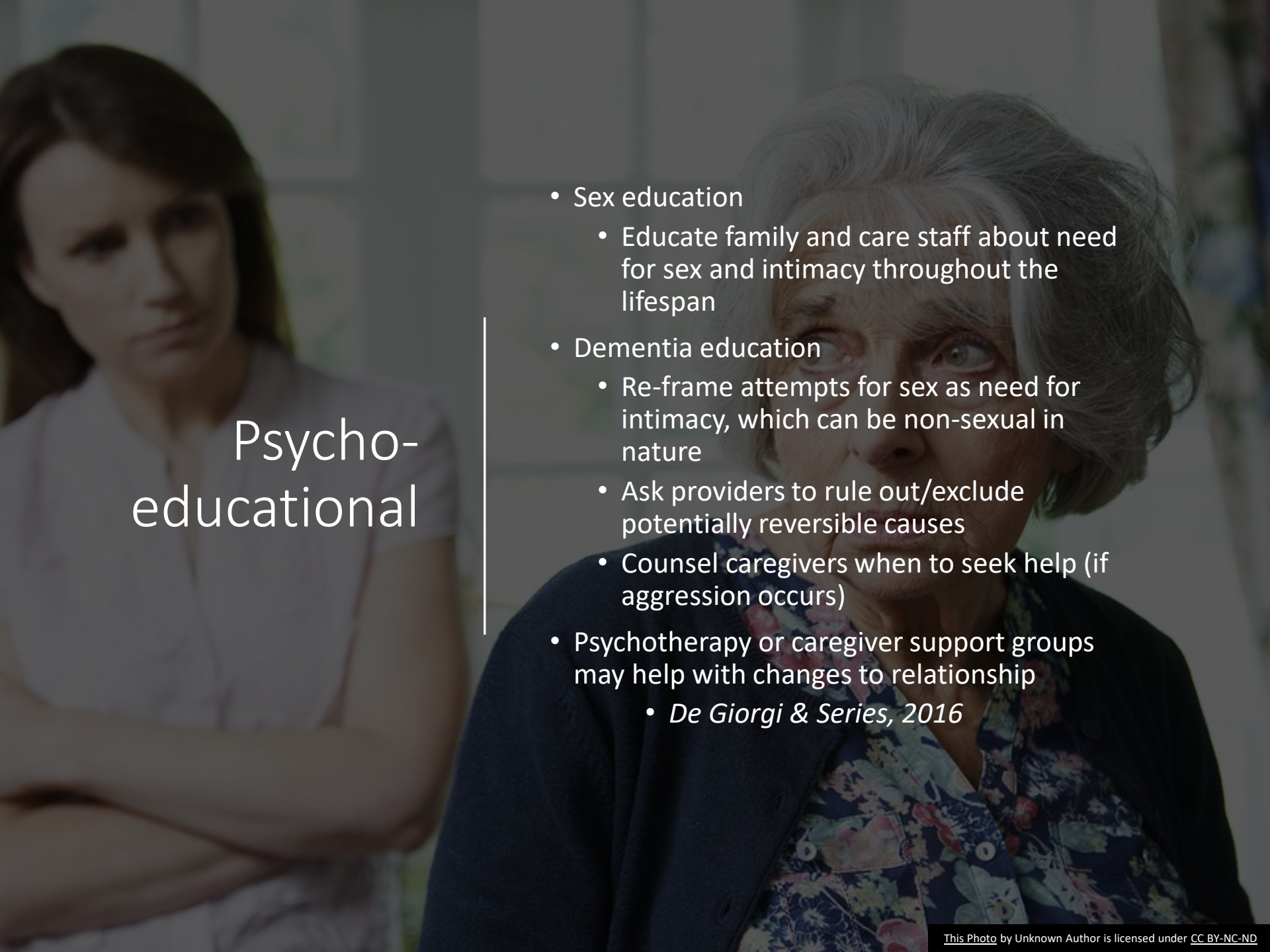
Behavioral approaches (continued)

- For a tendency to disrobe, clothing that more easily opens is a technique (*ethically challenging*)

- Cognitive behavioral therapy (CBT), if early stage
  - Educate about social norms
  - Explore underlying intentions of actions
  - Negative conditioning techniques

https://best-alzheimers-products.com/adaptive-clothing-dementia.html





Psycho-educational

- Sex education
  - Educate family and care staff about need for sex and intimacy throughout the lifespan
- Dementia education
  - Re-frame attempts for sex as need for intimacy, which can be non-sexual in nature
  - Ask providers to rule out/exclude potentially reversible causes
  - Counsel caregivers when to seek help (if aggression occurs)
- Psychotherapy or caregiver support groups may help with changes to relationship
    - *De Giorgi & Series, 2016*

Intimacy in spite of disease

- "Expressions of love"
  - Care as opportunity for intimate touch
    - *Trudeau, Gately, & Mahoney, 2015*
- Non-sexual touch
  - Hugging, holding hands, massage
  - Watching a movie, reminiscing, sharing a meal
  - Provide opportunity for residents to touch or stroke non-sexual objects such as pet therapy, soft stuffed animal, or fake fur.

Sex, LTC & dementia

- Sex often problematized in LTC settings
- Very few LTC staff receive training to address sex
- Lack of guidelines, which may include:
  - Shared rooms for couples
  - Privacy for those wanting to participate in sex
  - “Knock first” policy
  - **Dignity, privacy, equal treatment for all residents, including LGBTQ residents**

LGBTQ older adults

- Not all older adults are heterosexual!
- LGBTQ older adults with dementia more likely to experience social isolation
- Ageism + homophobia + stigma associated with having dementia
- Experience specific health related disparities (Healthy People 2030)
  - Increased risk for poor general health, disability, and mental distress

LGBT - Healthy People 2030 | health.gov

Dementia & sexual abuse

- Sexual elder abuse
  - Physical sex acts
  - Showing pornography
  - Forcing the person watch sex acts
  - Forcing elder to undress
- Signs of sexual abuse
  - Bruises around breasts or genitals
  - Unexplained venereal disease or genital infections
  - Unexplained vaginal or anal bleeding
  - Torn, stained, or bloody underclothing

http://www.helpguide.org/mental/elder_abuse_physical_emotional_sexual_neglect.htm#type

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Further Reading on Sex and Older Adults

Gerontologist, Vol 63, Issue 2 (*March 2023: https://academic.oup.com/gerontologist/issue/63/2

Clinical Gerontologist, Vol 44, No 3 (2021): https://www.tandfonline.com/toc/wcli20/44/3

Case

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QUESTIONS

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