Narcolepsy and Aging: Optimizing Health and Happiness

Lois E. Krahn M.D.
Mayo Clinic
Outline

• 2016 - 2017 were productive years for new research on this important topic

• Recent studies of aging patients with narcolepsy

• Discuss the findings and challenges

• Strategize how to age well
2017 Study
Narcolepsy and Aging

Center for Sleep Medicine, University of Copenhagen, Denmark

• Records for a national group-
  • Danish National Patient Registry
  • 1174 people with narcolepsy age 60 or older
  • 45% men, 55% women
• Compared to a group of people without narcolepsy by age/gender/geography
  • Jennun et al, Sleep Medicine, 2017
Living Situation

- No differences between the people with narcolepsy and controls
- 52% married or co-living
- 48% single
2017 Danish Study
People age 20-59
People age 60 or older

• People with narcolepsy had more medical problems
• They were more likely to have multiple coexisting problems
• They sought out health care more often
• These problems were present before the diagnosis
• Also after the diagnosis
• The list includes…….
Danish Study

- Infections
- Neoplasms
- Diabetes and related disorders
- Psychiatric issues
- Neurologic problems
- Pulmonary issues, including Obstructive sleep apnea
- GI
- Musculoskeletal issues (include back issues)
- Skin concerns
Danish Study

- Patients with narcolepsy had a higher death rate than controls, especially for people 60 and older

- Odds Ratio overall over a 17 year period was
- People aged 20-59 was 1.35 (95% CI, 0.94-1.95, p=0.106)
- People aged 60 and older was 1.38 (1.12-1.69, p=0.002)
Comments

• The opportunities for sleep diagnostic testing in Denmark are limited

• Narcolepsy was diagnosed years after disease onset

• They did not require a certain means of establishing the diagnosis –
  • unknown with or without cataplexy

****Did all of these people have narcolepsy? ****

• Some of the medical problems began before diagnosis

• Could these have been prevented if the narcolepsy been treated sooner?
2016 Study: Narcolepsy with Cataplexy in Patients over 60 years

• Charles University, Prague Czech Republic

• Records for a Sleep Medicine Center providing long term care to patients with hypersomnia
  • Patients 60 yrs. old or more invited to participate, mean age 72 yrs.,
  • 42 people with narcolepsy, all had cataplexy 43% men, 57% women
  • Compared to a group of people without narcolepsy by age/gender
    • Kovalska et al, Sleep Medicine, 2016
Study Plan

• Long interview about narcolepsy
  • Intensity of sleepiness by decade from onset
  • Severity of cataplexy
  • Duration of sleep during a 24 hour day

• Assessment of overall health, social life

• Questionnaires and physical exam
Characteristics of the People with Narcolepsy

- Onset, age 27 years
- Diagnosis, age 40 years
- 43% men, 57% women
- BMI 31.5 (peaks when people in their 60’s)
- 45% vivid dreams, 45 sleep paralysis
- 52% obstructive sleep apnea
- None, central sleep apnea
Characteristics of the People with Narcolepsy

• 88% on treatment for narcolepsy
  • Modafinil > stimulants >> sodium oxybate

• 50% on antidepressants

• More nicotine use

• Equal rates of alcohol and caffeine use
Findings

- Patients with narcolepsy and cataplexy had lower levels of physical activity and physical fitness.
- They were also more likely to have:
  - hypertension
  - type 2 diabetes
Findings

• No difference in memory problems
• More controls had a history of treated depression
• More patients with narcolepsy scored high on a depression survey (Geriatric Depression Scale)
  • Did they have current depression?
  • Or does sleepiness look like depression?
Findings

• No differences in the frequency of seeing family and friends

• No difference in level of participation in sports or hobbies
Cataplexy

- 12% had cataplexy “disappear” (> 5 years)
- 2 people had cataplexy reappear after 10 years without
- 24% described a “slight improvement” in cataplexy over the years
AGING WELL
Changes over time

- As we progress from age 20 to 40 to 70
- Physical changes - declining eyesight, smell etc
- Not all change represents loss!
- By age 70 we are more patient, more tolerant, more accepting of ourselves and others
Changes over time

• 70 year olds are more likely to understand every event has a past and a future → more wisdom

• At age 75 our IQ’s are the same as at age 20 (with the exception of some word finding difficulty after age 30)

• Mental deterioration before age 80 reflects disease, not the normal aging process
Successful coping mechanisms of healthy persons age 70-95

- Berlin Aging Study (1999) older persons
  - increased serenity (faith, acceptance, allowing someone else to take over)
  - increased spirituality
  - coped using humor
  - compared oneself with others more severely affected (keeping things in perspective)
Study of Adult Development

• Based on the contributions of George Vaillant M.D.

• Extensive study of adults over time looking at both physical and mental health

• Identified reasons for adaptation and decline
Study of Adult Development

- Studied a cohort of 237 Harvard college students and 332 inner-city youth for 60 years
- Simplified the analysis by restricting the sample to white American males born 1918-1932
- Psychosocial data collection every 2 years and physical exams every 5 years
Study of Adult Development

- Compared the healthy college and inner city participants at age 70
- Contrasted the healthy with the sad or sick as well as with the deceased
Factors predicting mental and physical health at age 70-80

• Uncontrollable factors
  • parental social class
  • family cohesion
  • major depression
  • ancestral aging
  • childhood temperament
  • physical health at age 50
Factors predicting mental and physical health at age 70-80

• Factors involving some personal choice
  • alcohol abuse
  • smoking
  • marital stability
  • exercise
  • weight
  • coping mechanisms
  • education
Predictors of excellent health at age 70-95

• High level of education (reflects self-care, successful planning and social class)

• Having an extended family network

• Absence of alcohol abuse

• Limited smoking
Psychological coping mechanisms

• Healthier men used several strategies to cope with stress
  • humor
  • suppression
  • anticipation
Predictors of successful aging

• At age 50
  • warm marriage
  • absence of major depression
  • good physical health

• Not as significant
  • weight, ancestral longevity, childhood environment and warmth
Predictors of poorer health at age 70-95

- Defined as dependence, being bedridden and dissatisfaction with life
  - Trouble walking
  - Poor vision
  - Older age
  - Dementia
  - Depression
Factors predicting mental and physical health at age 70-80

• **Bottom line**
  - Avoid alcohol abuse
  - Avoid tobacco
  - Avoid depression
  - Seek intellectual stimulation
  - Strengthen one’s marriage
  - Develop mature coping mechanisms
Factors predicting mental and physical health at age 70-80

• One can have great control over one’s future

• If depression develops intervention/treatment is possible
Over the lifetime

• “Adding life to years, not just more years to life”

• James Fries 1955