Clinical Aspects of Aging with a Disability: An Overview

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Disclosure: Numotion is a US-based wheelchair/complex rehab technology provider

“The universe is made up of stories, not atoms.”
Muriel Rukeyser
1913-1980
Goals of this talk......

- Increase understanding of some of the secondary conditions encountered when aging with a disability
- Learn how that information can be applied in the clinic process
- Learn where to find research to support clinical interventions
If you work in the field of complex rehab, you need to be aware of the effects of aging on those with acquired as well as childhood disabilities, whether you are an adult therapist OR a peds therapist.
Past to present

- Must understand client’s diagnoses and conditions and the effects aging can have on them
- Must understand how these changes relate to function and incorporate into practice
- Time since disability onset is what counts: eg, if someone sustains SCI at age 15, at 20 years post they are only 35 years old.
Understand the Past To Make Sense Of The Present

- 1900-2000: ave life span from 47 to 77 yrs
- Same time period dramatic increase in survival and lifespan for people with disabilities.
- 1945-2 years post SCI; 2011- 85% of typical lifespan
- Old rehab practices; “Use it or Lose It”......”Conserve to Preserve”: Barry Corbett
  (New mobility)

(KEMP, ET AL. WHAT THE REHAB PROF AND CONSUMER NEED TO KNOW. PHYS MED CLIN NA - 2005)
The Past to the Present.....goals after survival

- WWI - Survival - independence within an institution
- WWII - birth of rehab - goal was independence in the home
- 50’s, 60’s - Use everything you have to fit in
- 60’s, 70’s - Use it or lose it (professional athletes every day)
- Disability rights movements, ADA 1991
- New era of considering planning for the long run
Types of Aging

- Usual, pathologic and successful aging
- Usual aging characterized by decreasing reserve with increasing age (genetics, environment and personal choices play a role)
Aging with a Disability

- For disabilities, the age acquired makes a difference (infant/ adult- differences in social participation, opportunities)
- Often experience changes in function 15-20 earlier than non-disabled peers
- How aging with disability intersects with genetic aging not well understood
- Very clear not a static process
Some examples from the literature
Psychosocial

- Initially begun in 1973 by Nancy Crewe at U of Minnesota
- Most recent follow up in 2013
- 759 surveys- 71.9% male: ave age 27 @ time of injury, 53 at time of study. Ave 27 years post.
- 4 important trends:
  - The survivor effect- increased social well-being before injury even more important than medical adjustment
    - Participation in social activities outside the home and the ability to have SITTING TOLERANCE
  - Change in trends in activities, satisfaction & health over time
  - The multi-faceted nature of well-being
4 Problems that often bring people back into the medical model:

- Fatigue
- Weakness
- Pain
- New pressure sores
Fatigue

- **Central**: generalized lack of energy; exhaustion
- **Peripheral**: muscle weakness
- **Mental**: inability to focus or stay alert

- Fatigue in the general population: 15-20%
- Fatigue with disabling conditions- 3X higher
Fatigue & aging with disability

- Fatigue can be extremely debilitating; often insidious.
- People give up a little here, a little there.
- People give up “extras” so they can do essential functional tasks.
- Participation in work/leisure may decrease to conserve energy for basic activities.
Fatigue

- (2001) RRTC on Aging with a disability
- 62-78% of people with CP, RA, PP and SCI complained of Central fatigue.
- Prevented sustained physical function in:
  - RA - 100%
  - CP - 98%
  - PP - 87%
  - SCI - 65%
- Interfered with duties of 2/3 of those with CP and ¼ of those with PP
Fatigue


- Used PROMIS* – Depression Short form
  - Patient Reported Outcome Measurement Information System
- N = 1836 people in Washington state
- Findings: Individuals with disability are not only at a greater risk to experience fatigue but this risk, relative to normative values, increased with age
- Further research needed

*PROMIS- initiative by NIH (US) to develop measures of key symptoms & outcomes applicable to range of chronic conditions
Musculoskeletal - Weakness

- 150 people, average 3 years post injury
- 11% recognized a loss of strength when they cannot perform a regular functional task (falling)

Thompson & Yakura, Topics in SCI Rehabil. 2001. 6(3): 69-82
“Functional Impairment Syndrome”

- RRTC studied over 600 people w/ varied diagnoses who had constellation of pain, fatigue and weakness
- Occurs as a syndrome and usually is the beginning of changes in function in major activities.

Thompson and Yakura. AGING RELATED CHGS IN PERSONS W/ SCI. TOPICS SCI REHAB. 2001
Post Polio Syndrome

- Most survivors in developed countries older than 60. Indian subcontinent, where just eradicated, thought to have millions of young survivors

- Cause appears to be long term stress on motor neurons causing premature degeneration. Those who had most paralysis, then functional recovery, at greatest risk.

- Results in:
  - Joint pain
  - Muscle weakness
  - Fatigue
  - Respiratory and sleep complaints

- Combination causes a dramatic loss of function that far exceeds normally anticipated changes due to aging

Kemp and Mosqueda
Groce, M; Banks, L, & Stein, M. Surviving Polio in a Post-polio World. Social Science and Medicine, Vol 107, 4/2014, 171-178
Musculoskeletal System - Pain

- Individuals with physical disabilities tend to have degeneration of articular cartilage that is more significant due to overuse.
- In SCI, UE joints are often used for all functional activities to compensate for LE weakness/paralysis: 60-80% have pain, some debilitating.
- In CP, more widespread problem due to varying levels of spasticity and movement disorders
- Post polio, depends on what areas of the body are affected by paralysis or weakness, and which parts used to compensate.
Pain- SCI

- 239 people, ave. 37 years old, 12 years post.
  - 55% Tetraplegia had UE pain (46% shoulder)
  - 64% Paraplegia had UE pain (carpal tunnel/shoulder)
  - Interfere w/ one or more ADL’s

- Even a small change can cause decreased ROM, ie in shoulder. May be functionally equivalent to a higher level of injury; 46% of those with Tetraplegia and 36% of those with paraplegia experience shoulder pain.
Cerebral Palsy

- Arthritis - severe arthritis
- Contractures
- Increased skeletal deformities
- Incontinence
- Respiratory
- Fatigue
Pain in Cerebral palsy

- 179 adults with cerebral palsy
- 18% had pain that they rated as significant daily.

Murphy, et al. Med and Func Status of Adults w/ CP. Dev Med and Child Neuro 1995
- 101 w/ ave age 42. 50% had new pain; 76% had multiple skeletal problems
Pressure Ulcer Problems

- SCI Model systems database
- N=3361; about the same # of paraplegia as tetraplegia
- Steady for the 1st 10 years, increase at 15
- Aging related decrease in muscle mass and vascularity? Neuro impaired skin with long term structural changes
- AGE AT TIME OF INJURY MORE SIGNIFICANT

- CHEN, ETAL
Traumatic brain injury

- Colantino, et al
- Retrospective cohort design. Med records of 286 persons with TBI who were injured between 1974 and 1984 (as well as 20 informants).
- Mean age at injury 29.9: at time of study, 44.
  - Prevalence of arthritis, HO- many were in MVA’s originally and had multiple injuries.
  - Difficulty with sleep
  - Difficulty with “nerves”
  - Decreased vision/hearing
The Evaluation Process for the Experienced Wheelchair User

- Interview
- The way one approaches someone who has been living with a disability is different than someone new to the process.
- Mat Evaluation
- Functional Evaluation
- Trial Equipment
- Prescription
Clinicians and Suppliers should……

- **LISTEN!!!!**

- Anticipate changes based on what you know about common problems (don’t ask, can’t find out)
- Change in abilities, probe for details.
- Difficulty performing a task that was once part of their routine - question further.
Interview

- Why are you here? (routine, special?)
- Medical History
  - Date of onset of injury or condition: reason for injury
  - Associated injuries
- Surgical History
  - Skin surgeries
  - Equipment History: how old is your equipment?
  - Observe equipment and how used
- Lifestyle factors
  - Strategies used for Activities of Daily Living (ADLs)
  - Home, work, other environments
  - Transportation
Functional Evaluation

- How ADL/functional skills are accomplished

  Such as….
  - Transfers (in home, car, etc..)
  - Toileting (at home vs. in public bathroom, etc..)
  - Look at current equipment and how “parts” are used. This includes:
    - How components are worn?
    - What patterns they are worn in?
Should asking more specific questions during interview

- Pain
- Fatigue
- Current ADL skill level - has it changed?
- Current functional skill level - has it changed?
Mat Evaluation - Overview

- Feeling limitations and how much force is necessary to support/provide corrective forces
- Elicit feedback from the client
Simulation and Trial Equipment

- Always simulate in some manner
- If you are modifying current equipment, simulate in current wheelchair
- If you are thinking of significantly increasing/changing support, must be done in conjunction with performance of key functional skills
- Ensure that you make good use of trial equipment
Wheelchair and Seating technology changes

- You are in this eval for the long haul. Never force or rush a decision. Be a police officer, rather than a firefighter.
- Be prepared to make good use of trial equipment: trying things “on the sly”

......78% OF 54 clients w/ functional decline had new equipment ID’d by therapists after assessment, whereas only 10% recognized this need before.

Thompson and Yakura
How suggestions of change are made makes a huge difference (without judgement)

Do ANY of us like to change things we’ve been doing for years?

Always going to be things we just cannot change

Possible vs feasible
REFER ON TO OTHER SERVICES
MD, therapy, orthotist, etc
Resources

References

- Kemp BJ, Mosqueda L: Aging with a disability: What the clinician needs to know. Baltimore, MD: Johns Hopkins University Press; 2004. (can be found on Amazon.com)

References


References:


References


References


- Groce, M; Banks, L, & Stein, M. Surviving Polio in a Post-polio World. Social Science and Medicine, Vol 107, 4/2014, 171-178