Clinical Aspects of Aging with a Disability: An Overview

"The universe is made up of stories, not atoms."
Muriel Rukeyser
1913-1980

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

Goals of this talk……

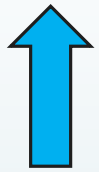
- Increase understanding of some of the secondary conditions encountered when aging with a disability
- Learn how that information can be applied in the clinic process
- Learn where to find research to support clinical interventions

- 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

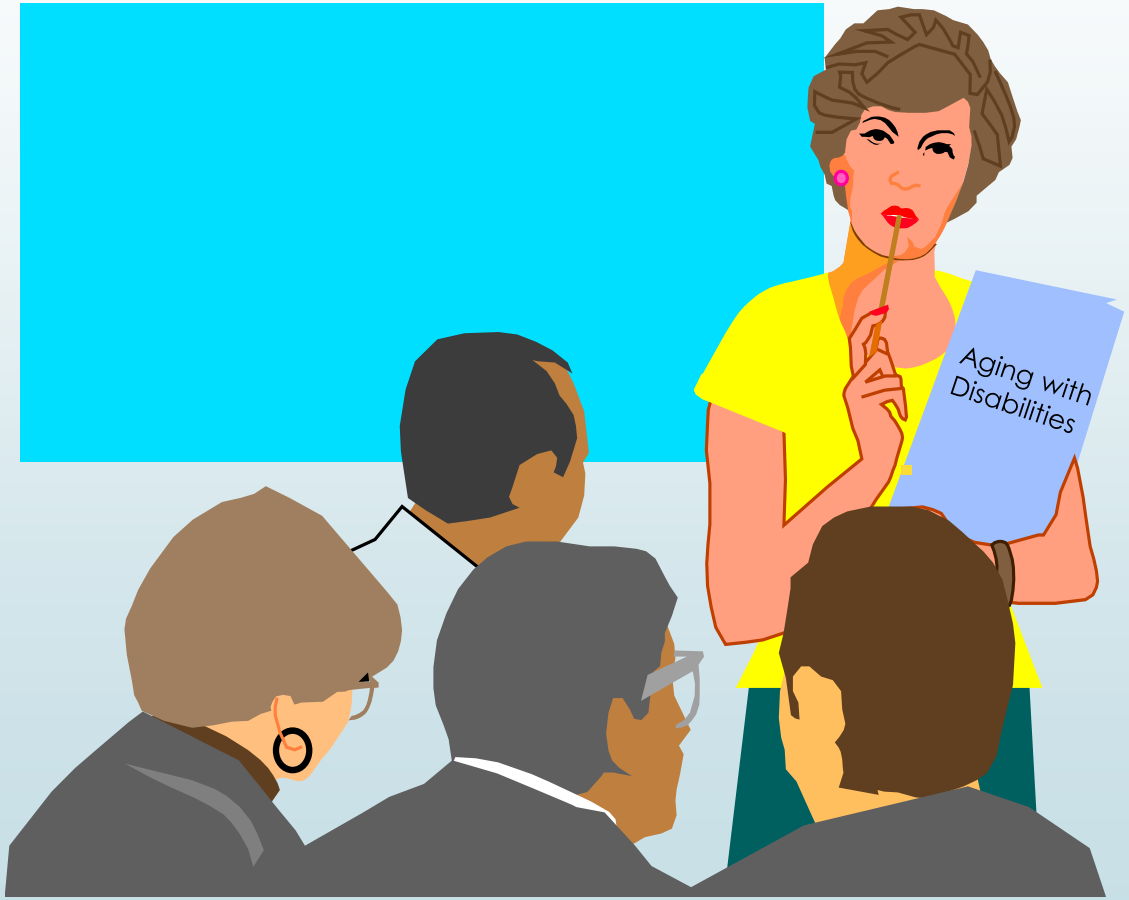
Types of Aging

- 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

Krause, et al. *SCI Longitudinal Aging Study: 40 Years of Research.* Topics in Spinal Cord Inj Rehabil 2015: 21(3): 189-200.

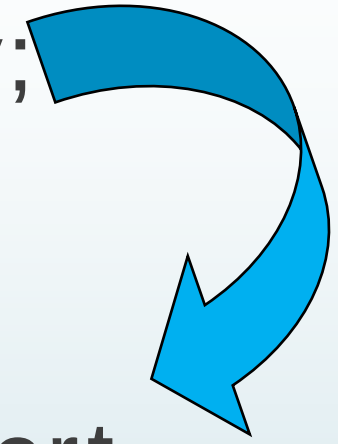
- Initially begun in 1973 by Nancy Crewe at U of Minnesota
- Most recent follow up in 2013
- 759 surveys- 71.9% male: ave age 27 @ time of injury, 53 at time of study. Ave 27 years post.
- 4 important trends:
  - The survivor effect- increased social well-being before injury even more important than 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

Cook, et al (2011)

- 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 need

*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

Sie, et al. Arch Phys Med Rehabil. 1992;73:44-48

- 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

Waters & Sie. Upper Extremity Changes with SCI Contrasted to Common Aging in the MSK System. Topics in SCI Rehabil. 2001; 6(3) 61-68.

  - 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.

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Cerebral Palsy

- Arthritis –severe arthritis
- Contractures
- Increased skeletal deformities
- Incontinence
- Respiratory
- Fatigue

Pain in Cerebral palsy

Andersson & Matteson. Dev Med and Child Neuro. 2001. 43: 76-87

- 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, ET AL.

Traumatic brain injury

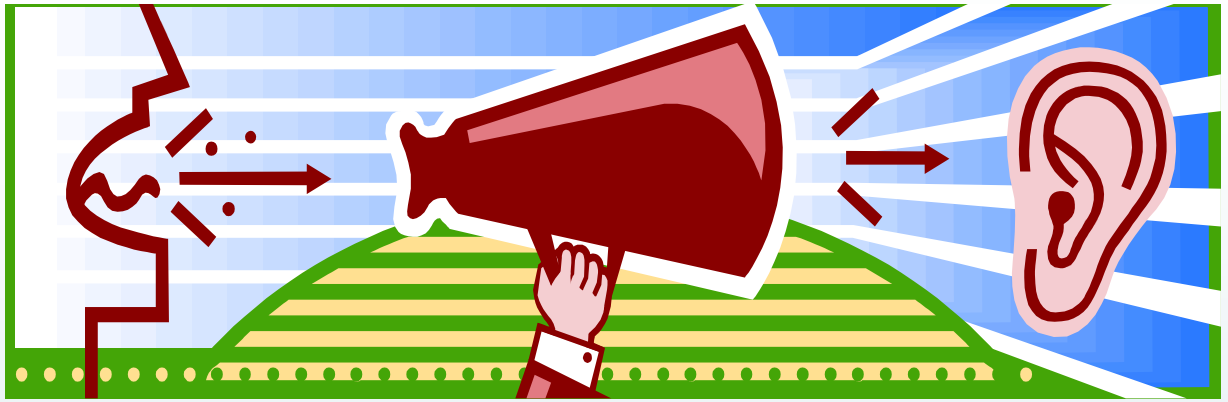
- Colantino, et al
- Retrospective cohort design. Med records of 286 persons with TBI who were injured between 1974 and 1984 (as well as 20 informants).
- Mean age at injury 29.9: at time of study, 44.
  - Prevalence of arthritis, HO- many were in MVA's originally and had multiple injuries.
  - Difficulty 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

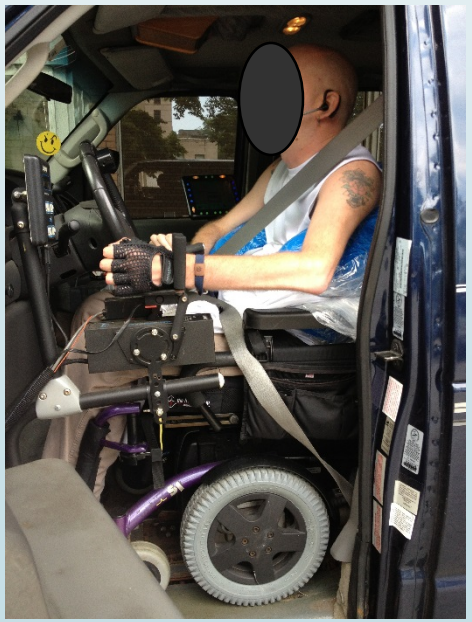
- Pain
- Fatigue
- Current ADL skill level- has it changed?
- Current functional skill level- has it changed?

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”

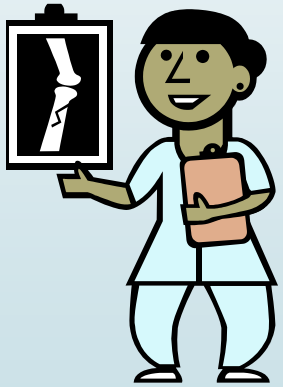
……**78% OF 54 clients w/ functional decline had new equipment ID’d by therapists after assessment, whereas only 10% recognized this need before.**

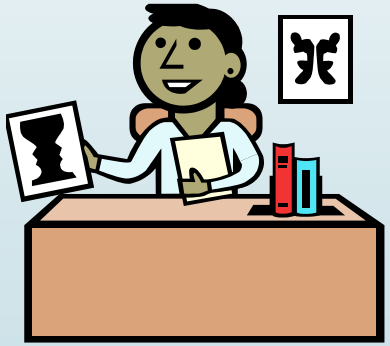
Thompson and Yakura

Wheelchair and Seating Technology Changes and Additions

- *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

- **PVA.org**; Clinical Practice Guidelines; Preserving Upper Limb Function in Spinal Cord Injury: Clinical Practice Guidelines for Healthcare Professionals. Consortium for Spinal Cord Medicine. 2005.

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