Aging with a Disability:Clinical Aspects We Can Use

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"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

Learning Objectives

- The participant will identify 4 research studies that can be used to inform clinical practice
- The participant will identify 3 factors relevant to aging with a disability to consider when interviewing the client.
- The participant will identify 2 considerations prior to making seating and mobility recommendations.

"The world henceforth will be run by **synthesizers**, people able to put together the right information at the right time, think critically about it, and make important choices wisely."

Brainyquote.com.
https://www.brainyquote.com/quotes/e_o_wilson_176377


Oh, the Places You'll Go!
Dr. Seuss

Conversations

- Complex, somewhat difficult conversations
- Starts with being armed with *information and an open mind*
- You must be armed with a willingness to *speak less, listen more*, and
- Learn how to ask open ended questions, without judgement (more about this later)

- 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 a therapist who works with adults OR children.*

Past to present

- Must understand client's diagnoses and conditions and the effects aging can have on them
- Rehab specialists must understand changes in function that can take place to 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.

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- push toward independence in community
- 60's, 70's- Use it or lose it; you had to fit in (professional athletes every day)
- Disability rights movements, US ADA 1991
- New era of considering planning for the long run: ~~Use it or Lose it~~……**Conserve to Preserve**

Barry Corbett, New Mobility

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)
- 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 Study

- 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
  - Multiple indicators of reflecting successful employment

Krause, et al. *SCI Longitudinal Aging Study: 40 Years of Research.*

Topics in Spinal Cord Inj Rehabil 2015: 21(3): 189-200.

Psychosocial: U of Washington Study

A recent study by Molton and Yorkston (2017) gathered 49 adults between the ages of 45 and 80. Diagnoses included muscular dystrophy (MD), multiple sclerosis (MS), post-polio syndrome (PP) and spinal cord injury (SCI). They conducted a focus group with the theme of what successful aging looked like to them. The researchers came up with 4 areas:

- **Resilience and adaptability**: The interviewees defined this as having a positive outlook and being able to adapt to changes.
- **Autonomy and choice**: Maintaining control over life decisions such as what kinds of adaptive equipment to use.
- **Social connectedness**: Strong relationships and being able to share experiences with peers.
- **Physical health and access to healthcare**: Being able to maintain physical wellness to continue to participate in desired activities. Not only having access but also having healthcare professionals who understand their disability.

Molton, I and Yorkston, KM. (2017). Growing older with a physical disability: a special application of the successful aging paradigm. J Geront: Social Sciences 72(2), 290-99.

4 Problems that often bring people back into the medical model:

- Fatigue
- Weakness
- Pain
- New pressure injuries

Fatigue

- General population- 15-20%
- People with disabling conditions- **3X** higher

Fatigue

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

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

"Disease Burden"

In the Study by Whitney, et al. (2018):

- Over the past few decades, the "global disease burden" has shifted from premature death to many years lived with a disability, and from the prevalence of communicable diseases to non-communicable diseases. (NCDs).
- For this study, they included 2 broad areas; Musculoskeletal morbidity (osteopenia, osteoporosis, osteoarthritis and Rheumatoid arthritis) and Cardiometabolic morbidity (stroke, hypertension, and cardiovascular problems that can include peripheral artery disease and heart failure).
- They looked at prevalence of NCDs in a sample of 452 people with CP and 448 people without CP, aged 18 - 30 years.
- The researchers found higher rates of these musculoskeletal and cardiometabolic issues in people with disabilities.
- 51% of participants had NCDs who scored at levels I-III on the Gross Motor Function Classification System (GMFCS), and 49% had NCDs who scored at levels IV and V .
- These musculoskeletal and cardiovascular conditions can greatly impact physical function.
- They also stated that by age 40-60 years, 60% of adults with CP have multiple secondary conditions - this is 1.5 to 2.9 times higher than the general population.

Whitney, et al. Noncommunicable diseases (NCD) and multimorbidity in young adults with CP: Evidence of early aging? Clin Epid. 10. 511-591. 2018.

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.

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

Musculoskeletal – Weakness
Cerebral Palsy

- Edward Hurvitz, MD, Cleveland Clinic
- Can therapy prevent functional decline?
- 8 wks, 40 mins/day, 5 days/ week
- Monitored at home via internet
- Reaching times improved as well as reversal times in the affected and unaffected arms.
- Tactile discrimination 50% better in affected arm.

Pressure Injury Problems

- SCI Model systems database
- N= 3361; about the same # of paraplegia as tetraplegia
- People with paraplegia more likely to be hospitalized
- Steady for the 1st 10 years, increase at 15
  - 15% at one year post injury
  - 30% by 20 years post injury

- CHEN, ET AL.

Traumatic brain injury

- Retrospective cohort design. Med records of 286 persons with TBI who were injured between 1974 and 1984 (as well as 20 informants).
- Colantino, et al
- 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

INTERNATIONAL CLASSIFICATION OF FUNCTION (ICF)

FIRST, THERE IS A HEALTH CONDITION (DIAGNOSIS)….

WHICH RESULTS IN…IMPAIRMENTS	WHICH RESULTS IN…LIMITATIONS	WHICH CAUSES….. AN INABILITY TO PARTICIPATE
Impairments are how the diagnosis affects body structure and/or function.	Limitations are how the impairment affects an ability to perform an activity	Decreased participation is how the limitations affect the client's ability to participate in activities that they need or want to do.
(abnormal tone, contractures, etc)	(such as an inability to sit, inability to reach upper shelves)	(such as an inability to cook a meal, drive, grocery shop)

Environmental factors and Personal factors

These play a role also. These are "**contextual factors**".

Environmental factors can include social attitudes, architectural characteristics, climate, terrain, among others.
Personal factors can include gender, age, coping styles, social background, education, past and current experience, overall behavior pattern, character.

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

The Evaluation Process for the Experienced Wheelchair User

- Interview
- The approach with someone who has been living with a disability is different than someone new to the process.
  - **WHY** are you here?
  - Questions about **pain, fatigue**
  - Has your function changed?
  - Questions about falls
- Mat Evaluation
  - What is **realistic** to accomplish?
- Functional Evaluation
  - **HOW** do you use your current equipment?
- Trial Equipment
- Prescription

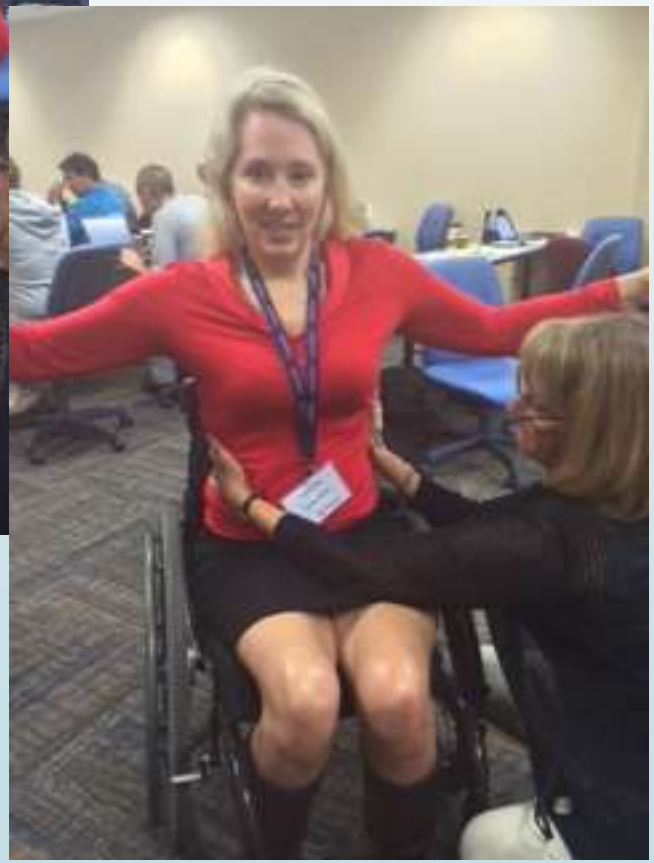
Molton and Matsuda (2016) suggest that questions about types of falls, when they occur, and whether they are associated with injuries are important.

This can inform if and when equipment and techniques are safe and functional.

Mat Evaluation - Overview

- Feeling limitations and how much force is necessary to support/ provide corrective forces, and watch client's reactions.

- Elicit feedback from the client



Through this, you will create REALISTIC expectations

Clinicians Rehab Technologists should……

- **LISTEN!!!!**

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

Non-verbal Cues: Reading and Delivering

- **Open-ended questions-**
- Adapting to a changing situations: e.g.: client does not follow or understand, ***so you change the way you explain things***
- Be aware of differences: culture, gender, age, emotional states, etc.
- Watch for cues over the course of your conversation.
- If you are talking to a client who brought their family member or caregiver, be sure to monitor their reactions as well. (shoulder surgery)
- Incongruences between verbal and non-verbal feedback: "check in" e.g.: ***"Are you sure you are ok with this?".***

Wheelchair and Seating Technology Changes

- *How* suggestions of change are made makes a huge difference
- 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

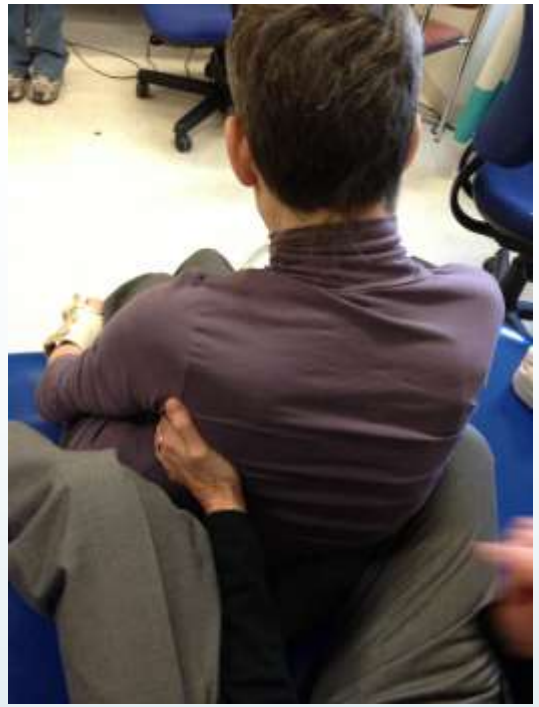
Wheelchair and Seating technology changes

- 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

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

Often, clients don't realize how much effort they have been putting into balancing and functioning until adequate support is provided (Taylor, 2017).

Trial Equipment

- Importance
  - How does it fit?
  - Does the client think it improves their ability to function? Are they comfortable? (young woman with CP)
  - Is it accomplishing what client/caregivers and team expected? This may not happen the day of the evaluation.

Ben Matlin- late 50's, SMA. Article in Washington post

"Before selecting my current chair, I did everything the right way. Instead of going to a wheelchair store, as I had previously where, in memory, a fast-talking, brochure-brandishing salesman took one look at my insurance and decided I needed "the Cadillac of power chairs" — I approached a specialized wheelchair clinic at an in-hospital rehabilitation facility.

In weekly visits over six months, I was measured and evaluated by a horde of physical and occupational therapists who showed me various options, brands and accessories to accommodate my slackening muscles. My disability had progressed, as it's wont to do, to a point where a standard joystick control was no longer an option.

Just about everything else, however, felt like a fight.

"You need a different type of headrest," I was told.

"But I like the kind I have."

"No. It hurts you."

It didn't. But I followed most of their recommendations, and when the new chair arrived, almost everything had to be changed. Seat cushion, armrest and, yes, the headrest. The monster chair didn't fit in my apartment elevator, so the footrests had to be modified. The driving harness had to be propped up with dense foam or I couldn't reach it. On my first drive, I crashed in my living room. Then the powerful chair tipped over backward at the first incline, so the center of gravity had to be shifted forward.

In short, until myriad alterations were made, my brand-new, state-of-the-art machine had effectively immobilized — dare I say "crippled"? — me. It took another year of tinkering to get it right."

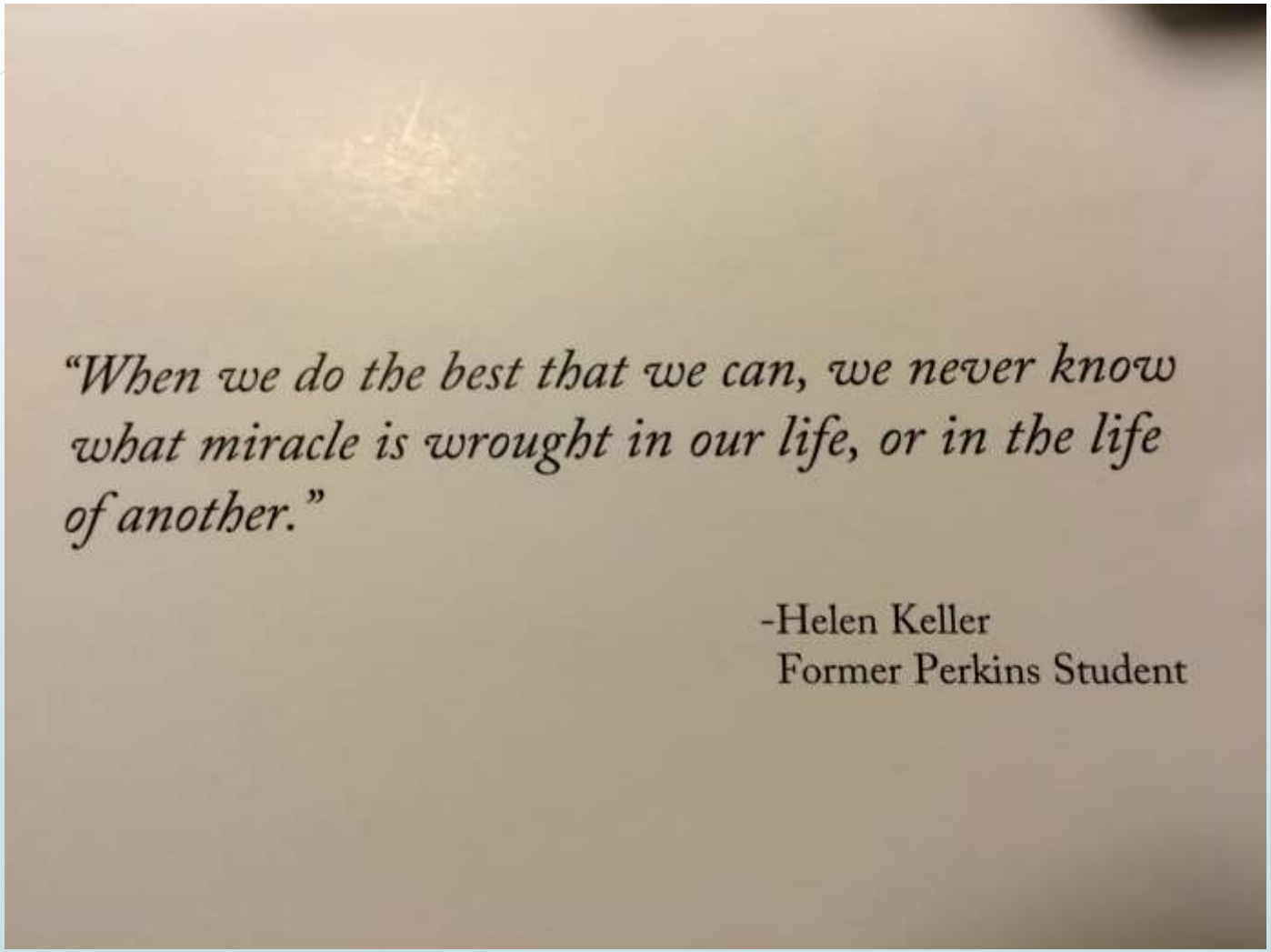
He still keeps his 37 year old powered chair.

Stairs to nowhere

- Giangreco, M.F. (2004). "The stairs didn't go anywhere!": A self-advocate's reflections on specialized services and their impact on people with disabilities. In M. Nind, J. Rix, K. Sheehy, & K. Simmons, K. (Eds.) (pp. 32-42).
- Personal space– human beings-
- Just. Listen.

- REFER ON TO OTHER SERVICES
- MD, orthotist, etc

Questions???


"When we do the best that we can, we never know what miracle is wrought in our life, or in the life of another."
-Helen Keller
Former Perkins Student

Thank you, acknowledgements and tips

- Includes information compiled from past presentations with **Mary Shea, David Kreutz and Jean Minkel**

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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