# Aging with Disability

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# "Aging isn't for sissies"

#### [License Plate Frame; Brian's Mom]

#### Brian

- Congenital disability (Cerebral Palsy- Spastic Diplegia)
- Heal cord release (age 6) Orthotics (age 3)-Canes (age 18)-Scooter (wheeled mobility) (age 30) Therapy (age 9-12); Self-Managing Knee meniscus tears/surgery Herniated lumber discs (persistent low back pain)

- Brian's Dad WWII disabled Veteran; Bilateral Lower-Limb Amputee - Prosthesis User, Cane & Crutches
- Brian's Mom

  - Non-Insulin Dependent Diabetes
     Late adult neurological compromise (un-diagnosed)
     Lower Limb Weakness (walking aids)

Give the Aging with Disability Talk?

#### **Overview on Aging**

#### Bio-Psycho-Socio-Cultural-Spiritual Model

- Behavioral Adaptation to Aging:
  - Interactions between organic (biological), psychosocial, and environmental variables
- Existing disability and aging
  - Newer attention to this phenomenon
  - "Risk Line" // optimal level of fitness vs. critical level of incapacity resulting in functional compromise
  - With disability
    - Narrow space between capacity and zone of change (lack of reserve)
    - Greater Vulnerability (fitness issues; disease processes)
    - Inexperience, new cohorts of disability, first-timers

#### Model of Aging with Disability

#### Roberta Trieschmann

- Health behavior and function with aging a "balancing act" - For persons with disability, "balancing is often increasingly
- tenuous with advancing age"
- Balance= f(P,O,E)= Homeostasis (natural tendency)
  - Psychosocial Variables
  - Organic (Biological) Variables
  - Environmental Variables
- Health Behaviors
  - Survival Skills (managing life)
  - Harmonious Environments (supportive contexts)
  - Productivity (meaningful engagements)

#### New Cohorts: Aging with Disability

- 1940's and 50's > #s and attention to "survivors" - Polio, Amputation, Spinal Cord Injury
- 1960's and 70's > medical survival, emergency care - Spina Bifida, Birth Injury (Cerebral Palsy), Head Injury, Heart Disease
- 1980's and 90's "Chronic Health" and Technology - Cancer, HIV/AIDS, Organ Transplant, renal/Heart-Lung care, Joint Replacement
- 2000's ? Gene Therapy?

### New Cohorts: Aging with Disability

- Expected long-term survival; unexpected (unknown) effects of time (aging)
- Claiming "static" vs. "progressive" (Zola: less distinct)
- Progressive but self-limiting (?)
  - Muscular Dystrophies (MD, ALS)
  - Cerebrovascular Disease/Stroke (CVA)
  - Chronic Obstructive Pulmonary Disease (COPD)
- Chronic and Unpredictable (?)
  - Multiple Sclerosis
- Cancer & Heart Disease - Arthritis

### New Cohorts: Aging with Disability

- Chronic but "non-progressive" or "static"
  - Polio
  - Cerebral Palsy
  - Spina Bifida
  - Spinal Cord Injury
  - Head Injury

#### Those with disability:

- Aging is a continuous process of adjusting to disability
- Nothing is "status quo"
- Experiences may be similar or disparate
- Little has been published
- New attention to living and aging with disability

### Science of Aging with Disability

- Rates of Aging:
  - 'Developmental Delay' ??
  - 'Aging Swiftly' ??
    - RATE: Normal aging effects accelerated
    - FORMAT: Features of aging vary
      - Presby's (vision, hearing, tactile)
      - Flexibility (range of motion)
      - Strength (reserves)
      - Cardio-pulmonary (reserves)
      - Psychosocial (depression & suicide)

### Aging with Disability Bibliography

- LeeAnne Carrothers, PT, PhD (2005)
  - Rancho Los Amigos National Rehabilitation Center [NIDRR, OSERS]
  - Diagnostic Groups: SCI, CP, Post-Polio, RA
  - Issues for People Aging with Disability (600 articles) Pain
    - Fatigue
    - Strength/Exercise
    - Bone Loss/Osteoporosis
    - Metabolic/Endocrine
    - Psychological Issues
    - Health/Health Care (Disparity)

### Examples

- Polio [and Progressive Post-Polio Muscle] Atrophy]
  - Initial recovery peaked at ≈6 years. Lived with polio for 30-40 years.
  - $-\approx 25$  year later; Health Decline
    - > fatigue, weakness in affected and previously unaffected muscles, muscle and joint pain, breathing difficulty
    - Functional decline: use of wheelchairs; trouble walking, stairs, transfers; bathing challenges

## Examples

- Polio [and Progressive Post-Polio Muscle Atrophy]
  - > PPMA with > initial severity, onset after age 10
  - General Health Compromises: Hypertension, respiratory disease, arthritis, heart disease
  - "Avoid Excessive Exercise"
- Why (not entirely agreed upon)
  - Single motor units: 100-500 muscle fibers
  - Polio: sprouting toward 1000-2000 muscle fibers
  - Worn out? Excessive wear and tear

## Examples

- Spinal Cord Injury
  - Ohry (1983): "Patients with SCI are subject to pre-mature aging.
  - Decrease resistance to infection (antibody response)
  - Silent Sepsis- hypothermia and leukopenia
  - Premature hypertension and arteriosclerosis
  - > incidence of bladder, prostate and colon cancers
  - Difficulty with regulation of body temperature, fluid balance, obesity - Long-term SCI: Cumulative Trauma Disorders (UL)

  - Pressure Sores
  - Suicide

## **Examples** (Generic)

Disability

- Musculoskeletal problems (PAIN) Tender sore joints, muscles, tendons
   Organ discomforts
- Osteoporosis - Cardiopulmonary Diseases
- Nutrition and Exercise
  - > problem with fitness

  - Excessive Weight
     Poor (non-nutritional) Diet
- Stress and Endocrine System
- > rate of wear and tear, accelerated tissue breakdown
- Psychosocial Complications Isolation (lack of meaningful participation)
  - Depression

### Examples (Generic)

Old vs. New Rehabilitation Philosophy (?) "Use it or loose it" vs. "Conserve it to preserve it"

#### Individual's health and fitness

- Access to fitness centers
- Dietary needs and resources
- National Center on Physical Activity and Disability
  - [http://www.ncpad.org/]

#### Contextual supports

- Universal Design (accessibility)
- Assistance Needs (informal and formal)
- Access to Assistive Technology (comsumer-ization)

## Who are the Elderly?

55

■ Elderly: "somewhat old"

longest span of any 'age period'

- Senior Discount
- Young Old 65-74 (56% Female)
- Old Old
- Oldest Old
- Centurion
  - ≥100+
- "Two-thirds of all the men and women who have ever lived beyond the age of 65 in the entire history of the world are alive today." -Age Wave Institute (1993)

85+

75-84 (61% Female)

(72% Female)

#### Why do we age? With or without disability?

- Physiologic Causes
- Genetic Causes
- Environmental Causes
- Not mutually exclusive - all could and do play a role

# Physiological

- Wear and Tear
- Excessive strain, abnormal movements, spasticity
- Metabolic rate in humans declines after-20's
- Aging by Program: cell reproduction has preestablished limits
- Homeostatic Imbalance
  - one thing (error) leads to another (with disability?)
- Cross-linkage theory
  - collagen breakdown- multi-system change

## Physiological

- Accumulation of errors
  - new cell reproduction errors add up to faulty systems (Genetic re-cycling 7-10 times in a lifetime)
- Accumulation of metabolic wastes
- do not shed enough of our used cells
- Autoimmunity
  - advancing destruction of 'self'

## **Genetic Aspects**

- Family patterns of longevity
  - monozygotic twins more similar in patterns of aging than dizygotic twins
- New findings of genetic traits that 'predispose' some people to diseases
  - Breast Cancer (<10%)</li>
  - Colon Cancer (<30%)
  - Alzheimer's Disease? (Down Syndrome)

## **Environmental Factors**

- Mortality rates differ
  - Cross cultural differences within USA
     Blacks live fewer years than Whites
- Historical time differences
  - Public health versus medicine
  - Causes of death 1930's vs. 2000's
  - Role models with chronic illness?

## **Environmental Factors**

- Historical Events and Time
  - Culture-Regional differences in USA (diet, exercise & stress?)
  - Social and Natural disasters
  - Radiation Testing
  - Use of Pesticides
  - HIV
  - ???

## What impacts people?

- Nature vs. Nurture
- Stability vs. Change
  People become more
- different as they ageIncreasing Diversity among older adults
- Counter to Youth's Myth











## **Disability Key-points**

- Older Women > disability reporting than older men
- Blacks > disability reporting than whites
- Living alone or with relatives > disability reporting
- Medicaid recipients, Medicare, Private
- Outside metropolitan areas > disability reporting
- Southern U.S. > disability reporting than Western U.S.

## Disability Issues to Assess

- PROMIS Project: NIH Roadmap
- The Patient Reported Outcomes Measurement Information System (PROMIS): Tools for assessment
- Self-Reported Health [Physical, Mental, Social Health]
   Fatigue
  - Pain
  - Anxiety
  - Depression
  - Anger
  - Sleep/Wake Disturbances
     Social Roles
  - Discretionary Social Activities

### 5 Themes in approach; older adults

- Medical-Physiological
- Prevention (primary and secondary)
- Focus on Function
  - Context of ability (adaptive functioning)
- Promotion of Self-Care
  - Control over care decisions (Internal LOC?)
- Personal Context (Informal care providers)
- Rehabilitation in the Community
  - "Aging in place" (Universal Design/Adjustments)

# Therapeutic Approach

- Relationship between the <u>Individual</u> and his or her <u>Environment</u>
  - physical, social, spiritual
  - "Functional performance is behavior, [and] behavior is the outcome of the interaction of the person and the environment"

Betty Hasselkus, PhD., OTR Univ. of Wisconsin- Madison

#### A few suggested reading & references

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