



“Dealing with problems that we did not know would exist: A doctor-patient partnership”

Does the Physician have a Chance to Help This Guy?

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# First, Seek to Understand

- Can I figure out what Duncan's problems really are, even though he can tell me?
- Will he really tell me the whole story, especially on the first visit?
- Even if we can agree on a problem, will we agree on a treatment strategy?
- Will the treatment uncover or cause a new problem?

# Can We Identify the Problems Correctly?

## Questionnaire for Aging CP

- Structured Questionnaire of 54 adults with cerebral palsy (age range 25-36 years) and 48 physicians in the Netherlands
- Patients reported: pain (59%) and joint deformities (19-57%) as the biggest problems
- Rehabilitation physicians reported: pain (88%), joint deformities (86%) and fatigue (76%) as being the most frequent CP related health problems in adults
- Is this agreement??

*Hilberink J Rehabil Med. 2007*

## Musculoskeletal pain in adults with cerebral palsy compared with the general population

- 406 out of 766 adults with cerebral palsy and no intellectual disabilities in Norway responded
- 49% females and 51% males age range 18-72 years (mean 34 years)
- Nearly 33% of the adults with CP had chronic pain vs 15% in the general population
- Older subjects had more pain
- Pain in adults with cerebral palsy was significantly associated with gender, chronic fatigue, low life satisfaction and deteriorating physical function

*Jahnsen J Rehabil Med. 2004*

# Aging In Cerebral Palsy Persons in France

- 562 persons responded: 56% male and 44% female, mean age 36.
- Motor disability was more important with age (50% at age 20 and 70% after 60).
- A total of 66% of the sample had cognitive impairment or mental retardation
  - (how does that compare to the other study?)
- 60% needed help when going outside, and 40% required assistance with eating, bathing and dressing
- 75% experienced pain and 50% felt depressed or lonely
- Medication use was higher in the sample than in the general population.

*Dauvergne Ann Readapt Med Phys. 2007*

# The problems we find seem to have some similarities

- It seems to depend on who you ask
- How you ask, Why you ask
- Some of the most serious problems I am struggling with don't seem to show up much in the literature
  - Cervical Stenosis, Cognitive Problems
  - Subtle problems with walking and the patient says “I don’t know why”

# Again, Seek First to Understand

- What if the initial function was not so good?
- How much of the problems are from aging?
- How many of the problems are the initial disease?
- Is there a new reversible or irreversible disease?
  - Cervical stenosis, early dementia, arthritis, deconditioning, thyroid, nutritional deficiencies
- How many problems are due to lack of social support?
- How many are related to psychological adjustment and could be easily treated?



# Will Doctors Bias Their Questions Towards Identifying Problems That They Can Try to Solve or Treat?

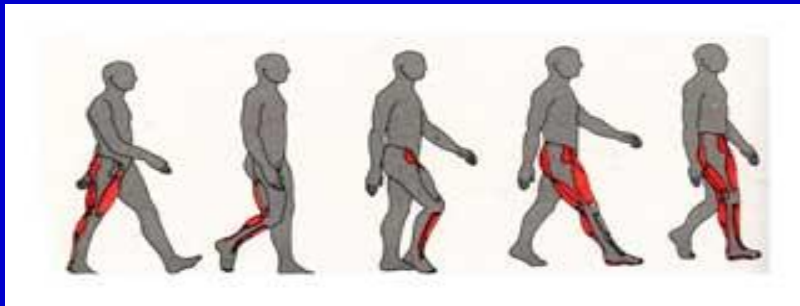
- Depression, anxiety, fatigue
- Easily treatable pain problems
- Side effects from medications that can be stopped
- Mobility Problems
  - Walking, tripping, weakness from deconditioning
  - Equipment deficits
- Activities of Daily Living (ADLS)
  - What Problems are they having?
  - Showers, toileting, dressing, managing money

## Treatment options That might improve function

- Physical Therapy
- Occupational Therapy
- Speech Therapy (swallowing , cognitive issues)
- Psychology
- Recreational Therapy
- Prosthetics and Orthotics
- Nutrition
- Other Equipment
- Medications

# The Ankle Is Too Plantar-flexed

The toe will catch during swing phase causing the person to fall forward.



# What Happens When the ankle Is Too Plantar-flexed? (I)

- This makes it tough to walk for several reasons
- When the leg is swinging the toe will occasionally catch causing the patient to fall forward
- When standing on the leg it keeps the knee straight which may prevent falls (this is not a problem)
- It may cause recurvatum of the knee which may be a problem
- The step length is shortened
- Walking speed is slowed

# What Happens When the ankle Is Too Plantar-flexed? (II)

- Energy consumption per meter walked goes up
- This may contribute to fatigue
- This may keep the patient in the house instead of participating in society
- This may contribute to depression or anxiety
- This may cause the patient to come to the doctor
- This may contribute to increased health care utilization

# What the Heck am I Babbling About??

- Straightforward problems in the leg can affect the entire person, their family, and society
- When looking for solutions to the problem in the leg, the whole person and the whole system should be taken into consideration
- All will be affected whether we admit it or not

# Treat the patient who has the disease, not just the disease in the patient

- This can seem obvious
- Try to figure out what the patient really wants
- Is the cure worse than the disease?
- Will Quality of Life Improve?

# What can be done about a Leg that does not work right?

- Ankle is too plantar flexed
- The Gastrocnemius (calf) is too strong
  - Spasticity from CNS injury make the muscle contract all day and night
- Then Anterior tibialis is too weak
- There is a contracture (shortening) of the gastrocnemius
  - The ankle is plantar flexed all night and much of the day
- The ankle joint has a mild contracture (not a huge problem)



# Options for Treatment of the Plantar Flexion Contracture of the Ankle

- Stretching
- Anti-spasticity medication
- Ankle Foot Orthosis (AFO)
- Pressure Relief AFO (PRAFO) at night
- Botulinum Toxin Injection to Gastrocnemius
- Surgery

# Options for Treatment of the Plantar Flexion Contracture of the Ankle Ankle Foot Orthosis (AFO)



# Pressure Relief Ankle Foot Orthosis (PRAFO)



# What about the Fatigue?

- Are the problems due to brain dysfunction?
  - cognitive decline, medication side effects
- Could the brain dysfunction be due reversible psychological issues such as depression, anxiety, fatigue?
- Will a medication such as a stimulant or antidepressant help with concentration and fatigue?
- Will exercise help or hurt?

# Individualized Exercise Program May Be Able to Improve Quality of Life

- Some Questions need to be considered
  - Aerobic – which muscles and joints can be exercised in this person?
  - How long can they exercise? What about cardiac precautions?
  - Non aerobic exercise – which muscles need strengthening?
  - Which muscles need stretching?
- How do we help this person actually exercise instead of talk about it? (Motivation Counts)

“Healing is a matter of time, but it is  
sometimes also a matter of  
opportunity”

**Hippocrates, *Precepts***  
*Greek physician (460 BC - 377 BC)*

# Physical Therapy

- Exercise
- Balance training
- Gait Training
- Use of ambulation Aides (Cane, Walker, Wheelchair for long distances, Motorized W/C)
- Training and assessment for orthosis
  - Ankle Foot Orthosis to keep ankle up and knee stable

# Occupational Therapy

- Activities of Daily Living (ADLs)
  - Dressing
  - Grooming
  - Bathing
  - Bathroom
- Instrumental ADLs:
  - Money management
  - meal preparation
  - planning of daily activities



# Speech Language Pathology

- Aphasia treatment and assessment
- Cognitive issues/ Retraining
- Swallowing disorders
- Instrumental Activities of Daily Living
- Dysarthria Treatment
- Communication Devices
- Hearing Problems

# Psychology

- Cognitive Assessment
- Neuropsychological Testing
- Cognitive Retraining
- Cognitive Behavioral Therapy
- Psychotherapy for mood disorders
- Instrumental ADLs
- Adjustment to Disability
- Family Adjustment

# Recreation Therapy

- Community Integration
- Transportation
- How to Function at Public Events
- Socialization
- Quality of Life Issues
- Integration With Family

# Vocational Rehabilitation

- Work Assessment
- Work Training
- Job Coaching (on the job training and adjustment)
- Work with Employer to help the person be successful and productive.

# Social Work

- Psychological Adjustment and counseling
- Assist with maximizing the system based resources to improve function
  - Insurance
  - Government options
- Identifying realistic and practical solutions that this patient can accomplish

# Nutrition

- Help with dietary restrictions
- Work with swallowing restrictions
- Work with Calorie restrictions
- Work with individual taste preferences