# Empowering Patient Autonomy for Extraordinary Outcomes

Stacey Zeigler, PT, DPT, GCS – Clarkson University

Diane Clark, PT, PhD – University of Alabama at Birmingham

# Examples for Today

- Ozer Payton Nelson (OPN) Method (Ozer,1999)
  - Allows for all diagnoses
  - Allows for all disciplines
  - Instructional design
  - Does not extend treatment time with the patient (once practiced)
  - Enhances professional communication skills
- Four Habits Model (Rao,2010)
  - A teaching and research framework that describes the sequence of important communication behaviors during the outpatient encounter from both the practitioner AND patient perspective

EMPOWERING PATIENT AUTONOMY FOR EXTRAORDINARY OUTOCOMES

# TOOLS

# Tools for Empowering Patient Autonomy

| Tool | Use | Other Information |
|---|---|---|
| | **Practitioner Directed** | |
| **Participation Method Assessment Instrument (PMAI)** (Baker,2001) | To determine attempts made to involve patients in goal setting | 21 items, requires observer or tape recording of session |
| **Decision Support Analysis Tool (DSAI)** (Guimond,2003) | To evaluate practitioners' use of decision support and related communication skills during a clinical encounter | Primarily used in research but criteria could easily apply to a self-directed quality improvement project |
| **Ottawa Personal Decision Guide** (OHRI) | Useful when a practitioner anticipates a person may have difficulty making a decision, or when a person expresses difficulty making a decision | Has A-Z inventory of decision aids with systematic process for current review<br>Has tutorial for providers and toolkits |
| **Ideal Patient Autonomy Scale** (Stiggelbout,2004) | Used to assess patient or practitioner views on autonomy | |

# Decision Aids (OHRI, O'Connor 2009)

- **Evidence-based tools** to prepare people to participate in making specific and deliberated choices among healthcare options in ways they prefer
- Used when more than one medically reasonable option - no option has a clear advantage in terms of health outcomes, each has benefits and harms that people value differently.
- Supplement but not replace practitioner counseling and aid decision making

# PROACTIVE

(Hunink, 2001)

**P**roblem **R**eframed
**O**bjectives
**A**lternatives
**C**onsequences
**T**radeoffs **I**ntegrate
**V**alues
**E**vidence

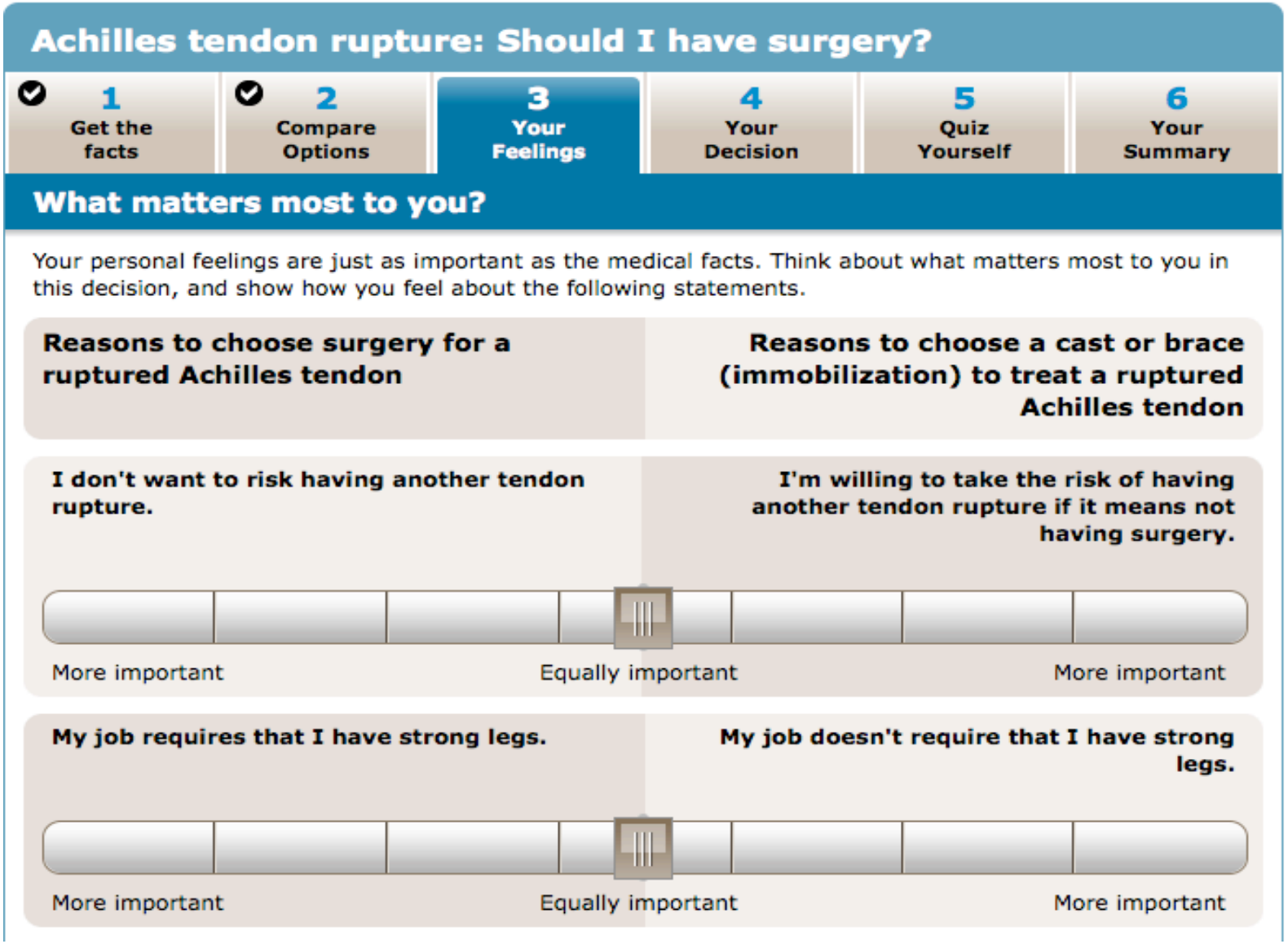
- Tool used to facilitate decision-making in the face of uncertainty
- Balance sheets
- QALY utility measures
- Probability revisions
- TreeAge Solutions Software

# Clinical Balance Sheet

| | Hip Protector Use | No Hip Protector Use |
|---|---|---|
| **Lifetime Risk of Hip Fracture** | 6.1% | 14.0% |
| **Hip Fracture Cost:** | Initial Management<br>Lifetime attributable cost | $19,000 - $66,000<br>$81,300 |
| Downsides | Skin irritation (5%)<br>Discomfort (5%)<br>Time to apply<br>Laundry issues | |
| Costs | Hip protectors ($80-300)<br>Cost of donning ($300)<br>Cost of laundry ($500) | Avoid cost of hip protectors |

(Clark D & White L, CSM 2010)

# Sample Decision Aid (Healthwise,2009)



# Cochrane Review of Use of Decision Aids
(O'Connor,2009)

- Decision aids increase people's involvement and are more likely to lead to informed values-based decisions
- Use simple (rather than detailed) decision aids
- Provide probabilities when possible (quantitative preferred)

# Considerations/Barriers in Development Patient Decision Aids

- Clinicians
  - Challenge to autonomy?
  - Don't recognize preference sensitive decisions
  - Evidence difficult to extract, interpret, communicate
- Practice
  - Logistics
  - Lack of time
  - Lack of reimbursement

- Patients
  - "Patients don't want to participate"
  - Variation in role preference
  - Health literacy challenges
- Resources
  - Need portfolio of appropriate decision aids
  - Time and skill

# Help in Using Decision Aids - IPDAS

- International Patient Decision Aids Standards (IPDAS) - http://ipdas.ohri.ca/
  - Collaboration of a group of researchers, practitioners and stakeholders from around the world.
  - Goal is to establish an internationally approved set of criteria to determine the quality of patient decision aids.
  - To join the Evidence Based Shared Decision Making listserv, please contact Dr. David Rovner at rovner@msu.edu.

# Tools for Empowering Patient Autonomy

| Tool | Use | Other Information |
|---|---|---|
| | **Patient Directed** | |
| **Patient Activation Measure (PAM)** (Hibbard et al, 2005 & 2008) | Assesses a patient's level of readiness to participate in the care process | 14 items that can be rated by the patient on a likert scale |
| **Control Preferences Scale** (Degner,1997) | Quickly assesses patient's desire for involvement | Can be excellent time saver and completed in waiting room |
| **Ottawa Personal Decision Guide** (OHRI) | Useful for links to pathology related decision aids | Has A-Z inventory of decision aids |
| **Impact on Participation and Autonomy Questionnaire** (Sibley,2006) | Used for evaluation of rehab outcomes for adults with long-term physical impairments | |
| **Ideal Patient Autonomy Scale** (Stiggelbout,2004) | Used to assess patient views on autonomy | Can equally be used to assess practitioner views |
| **FACIT Measurement System** (FACIT) | Distributes information regarding administration, scoring and interpretation of chronic illness questionnaires | Look particularly at FACIT – patient satisfaction scales |

# Patient Activation Measure (PAM-13)

(Hibbard et al, 2005 and 2008)

1. **When all is said and done, I am the person who is responsible for managing my health condition.**
2. **Taking an active role in my own health care is the most important factor in determining my health and ability to function.**
3. **I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition.**
4. **I know what each of my prescribed medications do.**
5. **I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.**
6. **I am confident that I can tell a doctor concerns I have even when he or she does not ask.**
7. **I am confident that I can follow through on medical treatments I need to do at home.**
8. **I understand the nature and causes of my health condition(s).**
9. **I know the different medical treatment options available for my health condition.**
10. **I have been able to maintain the lifestyle changes for my health condition that I have make.**
11. **I know how to prevent further problems with my health condition.**
12. **I know how to prevent further problems when new situations or problems arise with my health condition.**
13. **I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.**

# Control Preferences Scale (Degner, 1997)

**1.2**

**A**

I prefer that my doctor order tests or treatments for me based on my own personal wishes.

**B**

I prefer that my doctor order tests or treatments for me based on **my own personal wishes** after having seriously considered what he or she thinks is best.

**C**

I prefer that my doctor decide about which tests or treatments to order by equally weighing both my personal wishes and what my doctor thinks is best.

I prefer that my doctor order tests or treatments for me based on **what my doctor thinks is best**, after having seriously considered my personal wishes.

**D**

I prefer that my doctor order tests or treatments for me based on what he or she thinks is best.

**E**

OHRI IRHO

Patient Decision Aids



**Patient Decision Aids**
- For specific conditions
- For any decision

**Development Toolkit**

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# Ottawa Personal Decision Guide

The Ottawa Personal Decision Guide (OPDG) is designed for any health-related and/or social decisions.

It can help people assess their decision making needs, plan the next steps, and track their progress in decision making.

Several different versions of the OPDG are available:

1-page interactive PDF
(Fill in, save your answers, and print using Adobe Reader)

An application called iShould on Facebook.
iShould helps you make and share decisions with your friends.

# Impact on Participation and Autonomy Questionnaire (IPA) (Sibley, 2006)

| IPA Subscales | Question numbers |
|---|---|
| Autonomy indoors (7 items) | 1a, 1b, 2a, 2b, 2c, 2d, 2e |
| Family role (7 items) | 3a, 3b, 3c, 3d, 3e, 3f, 4a |
| Autonomy outdoors (5 items) | 1c, 1d, 5a, 6g, 10 |
| Social life and relationships (7 items) | 6a, 6b, 6c, 6d, 6e, 6f, 7a* |
| Work and education (6 items) | 8a, 8b, 8c, 8d, 8e, 9a |

Item number Impact on Participation and Autonomy (IPA) questions responses 'very good', 'good', 'fair', 'poor', 'very poor'

1a. My chances of getting around in my house *where* I want to are

1b. My chances of getting around in my house *when* I want to are

1c. My chances of visiting relatives and friends *when* I want to are

# The four subscales of the Ideal Patient Autonomy Scale (IPAS) (Stiggelbout, 2004)

**Scale I Doctor knows best:**

- If doctor and patient cannot agree on which treatment is best, the doctor should make the treatment decision.
- It is better that the doctor rather than the patient decides which is the best treatment.
- During the conversation, the patient must submit himself with confidence to the expertise of the doctor.
- The doctor can presume that the patient knows that people can die during serious operations.
- The patient should, without much information on the risk involved, confidently undergo an operation.

**Scale II Patient should decide:**

- The patient himself must choose between the various treatments.
- If a patient chooses a treatment with more health risks, the doctor should respect this treatment decision.
- It goes too far when the doctor decides which treatment is best for the patient.
- As it concerns the body and life of the patient, the patient should decide.

**Scale III Right to non-participation:**

- If the patient does not want to receive information about risks, the doctor should respect this.
- Patients who become afraid when thinking about the treatment decision should be left in peace by the doctor.
- Patients should have the right not to be involved in the decision on the treatment.

**Scale IV Obligatory risk information:**

- The patient has to be informed on all the risks involved in an operation.
- Before a patient consents to a treatment he should receive all information on the risks involved.

# Functional Assessment of Chronic Illness Therapy (FACIT)

- Subsets in Patient Satisfaction Questionnaire:
  - Explanations
  - Interpersonal
  - Comprehensive Care
  - Technical Quality
  - Decision-Making
  - Nurses (could be reworked to physical therapist assistants)
  - Trust
  - Overall

# FACIT-TS-PS (Version 1)

| Decision-Making | No, not at all | Yes, but not as much as I wanted | Yes, almost as much as I wanted | Yes, and as much as I wanted |
|---|---|---|---|---|
| Did your doctor(s) discuss other treatments, for example, alternative medicine or new treatments? | | | | |
| Were you encouraged to participate in decisions about your health care? | | | | |
| Did you have enough time to make decisions about your health care? | | | | |
| Did you have enough information to make decisions about your health care? | | | | |
| Did your doctor(s) seem to respect your opinions? | | | | |

***You*** *must be the change you wish to see in the world.*

- Mohandas Gandhi


- Stacey Zeigler, PT, DPT, GCS
  - Clarkson University, Potsdam, NY
  - szeigler@clarkson.edu
- Diane Clark, PT, PhD
  - University of Alabama at Birmingham
  - clark@uab.edu

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