Sustaining Rehabilitation Outcomes: Helping People Flourish

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Dun Laoghaire, Ireland    October 21, 2011
Objectives

◆ Discuss selected key challenges facing rehabilitation and chronic disease care

◆ Outline possible strategies to address these challenges

◆ Provide some examples of patient centered care and self-management initiatives that can improve and maintain rehabilitation outcomes
Acknowledgements

◆ Consumer Advisory Boards, study participants and my patients

◆ Colleagues and collaborators:
  – Johns Hopkins Project Restore
  – JHU Bloomberg School of Public Health: Ellen Mackenzie, Patti Ephraim, Renan Castillo
  – Amputee Coalition of America, American Trauma Society
  – National Rehabilitation Hospital – Simone Carton, Mary FirzGerald
  – NUI – Maynooth – Deirdre Desmond
  – DCU- Pamela Gallagher

◆ We gratefully acknowledge the support from the NIH and the Centers for Disease Control and Prevention under grants No. R04/CCU322981 and R01/DD000153, Dept of Defense and the Health Research Board of Ireland. The views expressed in this presentation are those of the author. No official endorsement by funding organizations is intended or should be inferred.
Developing Health Care Environment

- Changing health care models
- Changing health care problems
- Widespread acceptance of biopsychosocial model of pain
- Increased demands on patients and families
Traditional Health Care Models

- Characterized by several overarching themes
  - Focus on pathology
  - Focus on acute care
  - Primary focus on biology, with limited recognition of psychological and social factors in determining health
  - Emphasis on provider, not patient or behavior
Traditional Health Care

- Resulted in an exciting, successful, and almost exclusive, focus on pathology and repairing damage within a disease model

- Model highly successful in developing new treatments and reducing mortality and morbidity related to disease
Unintended Side Effects of Traditional Health Care Models

- Encouraged passive role by patients

- Reduced import of patient-provider relationship

- Cast individuals with an illness/disability as persons with defects
“Disability is not Inability”
“Treatment is not just fixing what is broken; it is nurturing what is best”.

Mihaly Csikszentmihalyi
Developing Health Care Environment

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Changing Health Care Problems

- The worldwide, US national and personal health care burden associated with chronic diseases and disability is increasing and will continue to increase.

- Individuals with chronic illness and disability are living longer and increasingly reside in non-institutional settings.

- Patients, along with their providers, are being held accountable for good outcomes.
Changing Health Care Problems

- The majority of health care resources have been directed at acute care not rehabilitation or improving independence.

- There is growing recognition of the increased role of persons with illnesses; however, the resources to support this increased burden are not well developed.

- Traditional medical care and the acute care system encourage a focus on “what the doctor is going to do”
What’s Wrong Here?

Acute care system

Chronic conditions
Developing Health Care Environment

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Biopsychosocial Model in Rehabilitation Outcomes

- Psychosocial variables - depression and coping strategies play a large role in explaining the variance in functional outcomes (Kennedy 2011)

- Meta-analysis indicate exercise can have a small to medium effect on HRQOL outcomes but cease after exercise is terminated (Chen & Rimmer, 2011)
Developing Health Care Environment

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The Work of Chronic Conditions

◆ Direct illness related work
  – Identifying providers, appointments, medication regimen, treatment regimen, rehabilitation program

◆ Indirect illness related work
  – Insurance issues, managing care, transportation, researching accessibility, advocacy, pursuing treatment options
The Work of Chronic Conditions

◆ Personal
  – reconstituting the self
  – accommodating to change

◆ Everyday life work
  – Additional time required for ADLs, developing work/school options, keeping up, covering up, pacing
The Work of Chronic Conditions

- Multiple types of work to accomplish
- Most of this work is invisible thus not valued
- Environment is often not supportive
- Untrained, unacknowledged and unpaid
- Unlimited commitment
- Patient and their families are the central workers
Health Care Challenges in Rehabilitation

◆ Long term patient outcomes in terms of employment and community participation are less than optimal.

◆ Length of stays are likely to decrease

◆ Availability of outpatient services in areas outside of major metropolitan areas are often limited
“The picture’s pretty bleak, gentlemen. ... The world’s climates are changing, the mammals are taking over, and we all have a brain about the size of a walnut.”
Responding to Challenges in Rehabilitation

 Called to modify our models of care and develop programs that will:

 – sustain the progress begun during the acute rehabilitation process

 – recognizes the need for patients and their families as central workers

 – assist health care system and providers in preparing and supporting patients and families
Responding to Challenges in Rehabilitation

1. Adopting collaborative care models for service delivery
2. Using patient centered principles in health care interactions
3. Developing self-management programs to prepare patients and families to carry the work of rehabilitation forward
4. Tracking long term outcomes that are important to patients, families and society
Collaborative Care Model (Wagner et al 1996)

Community
- Resources and Policies
- Self-Management Support

Health System
- Health Care Organization
- Delivery System Design
- Decision Support
- Clinical Information Systems

Informed, Activated Patient
- Productive Interactions

Improved Outcomes
- Prepared, Proactive Practice Team
Responding to Health Care Challenges in Rehabilitation

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Patient Centered Care (PCC)

- In 2001 the U.S. Institute of Medicine issues a report, *Crossing the Quality Chasm* – that challenged the American health care system to improve by addressing six major areas: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.

- PCC widens the focus from the patient’s acute medical needs to the needs of the patient as a whole, integration of care services, and patient education, family involvement, and emotional support.
Core Values of Patient Centered Care

- Empowers patients to become active participants in their own care
- Patients (and their providers) are held accountable for good outcomes
- Empowerment occurs through the interaction of “informed, activated” patients with “prepared, proactive practice teams”
Patient Centered Care

◆ Programs and services that empower patients to become active participants in their care respond to the need for patients to assume greater responsibility for their care and recovery.

◆ Strategies to achieve this goal include:
  – Training in self-management
  – Peer support and education
  – Computer-based health information
  – Redesign of health care delivery systems and infrastructure
Sheikh Zayed Tower
The Charlotte R. Bloomberg Children’s Center
Responding to Health Care Challenges in Rehabilitation

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Self-Management is a philosophy and tool

- Recognizes patients and families must be active managers of their health care

- Recognize individuals bring strengths and resources abilities persons bring to their medical problem

- Requires that clinicians serve as teachers, resources and guides

- Recognizes individuals may have different goals and that health enhancement is as important as symptom relief
Data on Self-management

- SM interventions have widespread application with illnesses and conditions in which chronic impairments, pain or disability are common (rheumatic disease, diabetes mellitus, headaches, back pain, amputation, SCI, MS).

- The strength of the efficacy and effectiveness data vary from condition to condition, the population studied and depending on the end point chosen. (Foster et al, 2007)
Self-Management Programs

Chronic Disease Self-Management Course & the Stanford Patient Education Center

http://patienteducation.stanford.edu/
Promoting Amputee Life Skills

A Program of the Amputee Coalition of America

Developed in collaboration with the Johns Hopkins University School of Public Health & Dept of Physical Medicine and Rehabilitation University of Washington Dept of Physical Medicine and Rehabilitation

Funded in part by the CDC
PALS Program

- 8 Weekly Group Sessions + Booster
- Facilitated by 2 Trained Leaders – one is a person with limb loss
- Emphasis in each session on:
  - Knowledge
  - Problem Solving
  - Skill Acquisition
  - Self Monitoring
  - Self Empowerment
PALS Groups

Average Group Size: 10

84% attended \( \geq 5 \) sessions

On average, participants attended 86% of PALS classes
PALS RCT Study

91 Eligible Groups Identified:
52 randomized
PALS RCT

**Randomize Groups**

- **PALS Group**: Baseline Interview, N=275
- **Support Group**: Baseline Interview, N=227

**Baseline**
- PALS Course (10-weeks)

**Follow-up**
- Post, 3 Month, 6 Months

**3 Months**
- Post, 3 Month, 6 Months

**6 Months**
- Post, 3 Month, 6 Months
PALS RCT: Results

- Participant Assessment
  - 95% would recommend PALS to a friend
  - 77% rated PALS more helpful than a support group
  - 58% rated PALS more important than other services provided
PALS RCT Results

♦ Outcome Assessment
  – three fold reduction in likelihood of depression
  – Increased self-efficacy
  – Increased positive mood
  – Less likely to experience limitations in function (Wegener, et al 2008)
Relative Advantages of Interventions Designed to Modify Behavior

High Efficacy

- Individual Counseling
- Group Therapy
- In Person SM
- On Line SM

Low Efficacy

- Self Help Guides
- Static Web Content

High Cost

Low Cost

Adapted from www.healthmedia.com
Self-Management in Ireland

Self-Management Programme
Johns Hopkins USA

People with amputations or SCI

Self-Management Programme for Patients in Ireland

NRH Practitioners

NUIM/NRH/DCU/JHU Team
SELF-MANAGEMENT PROGRAMME
Sustaining Rehabilitation Outcomes

◆ Think evidence based policy

– Utilize Care Standards (moderate support)
  » Evidence based care guidelines
  » CARF

– Link to State/local government (limited support)
  » Help them define disability as diversity
  » Link disability to their mission
    ◆ e.g. Self-management programs for persons with disability
Sustaining Rehabilitation Outcomes

◆ Create a Supportive Culture (moderate support)
  – Patient Centered Care

  – Build prepared, proactive teams
    » Ground providers and programs in PCC culture (moderate support)
    » Train providers (medical, nursing, rehabilitation therapies) in use of motivational interviewing techniques to guide patients in using self-management and engaging in adaptive health behaviors (strong support)

  Develop peer mentors (limited support)

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Sustaining Rehabilitation Outcomes

- Develop Continuum of Care – (strong support)

- Long term outcome monitoring – (moderate support)
  - Determine selected outcomes important to stakeholders – patients, families, society
  - Create system to monitor those outcomes
  - Maintain over years
Sustaining Rehabilitation Outcomes

◆ Partner with consumer and government organizations

◆ Explore how technology can extend your reach
Move from a focus on disease....

...to creating health