Patient and Family-Centered Care - Clients with Low Vision and their Families

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PFCC and Low Vision

- PFCC Definition and tenets
- History and barriers
- Low vision issues
- Rehab recommendations
- Future Directions
- LuLu’s journey with Marco
PFCC is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients and families. It redefines the relationships in health care.

PFCC practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge the emotional, social, and developmental support are integral components of health care.

(Institute for Family-Centered Care, 2006)
PFCC History

- Nursing forefront in FCC hospital movement over last 30 years
- Changes in maternity, NICU, Pediatric wards
- Education: Individuals with Disabilities Education Act (IDEA) - 1975
- Part C of the IDEA mandates FCC for birth to 3 population
Health care should be based on continuous healing relationships

Care should be individualized

It is important for patients to be involved in their own care decisions.

Patients and families should have improved access to information

Health care should become more transparent

Institute of Medicine-Crossing the Quality Chasm: A New Health Care System for the 21st Century, 2001
Patient-centered- providing care that is respectful and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.

An informed patient is a safer patient.

Nothing for you without you!

(Institute of Medicine, 2001a)
PFCC History

- IOM Report: Crossing the Quality Chasm
- Move to adult medical world
- Endorsed by major medical organizations and accreditation agencies
- Health Professions Education: A Bridge to Quality (IOM, 2003)
- Standard of care in peds world
- 2010- Family Advisory Council mandatory in Mass.
Overlap of Core Competencies for Health Professionals

Figure 3-1  Relationship among core competencies for health professionals.
Organizations Advancing PFCC Practice

- Agency for Health Care Research and Quality (AHRQ)
- American Academy of Pediatrics (AAP)
- American Hospital Association (AHA)
- Association of Maternal and Child Health Programs
- Bureau of Medicine and Surgery, U.S. Department of Defense
- JCAHO
- National Association of Children's Hospitals and Related Institutions
- National Patient Safety Foundation
PFCC Tenets

- Family constant in child’s or adult’s life
- Parent-professional collaboration
- Honor diversity of families
- Share information with family
- Family-to-family support
- Development needs of children
- Provide emotional and financial support to families
- Design systems that are culturally competent and responsive
PFCC Core Concepts

- Dignity and Respect
- Information Sharing
- Participation
- Collaboration
Barriers to PFCC

- Professional- lack of training in FCC (working with families, communication, diversity), may not view it as their “role”
- System- not designed to accommodate changes needed, reimbursement issues, logistical, staffing
- Family- cultural issues, language barriers, disability barriers
PFCC

- New way of working with families
- Places parents “in charge” of their children’s care
- Transition to PFCC has been challenging
- Changing role for health professionals
Families provide instrumental and emotional support for folks with low vision

- Instrumental- everyday assistance with ADL
- Emotional-providing comfort and encouragement
- Critical to individual’s adaptation to vision loss

(Bambara et al, 2009)
Studies on Instrumental Support (+)

- Shown to be associated with improved life satisfaction, decrease in depression, better adaptation to loss (Reinhardt, 2001)
- Increased use and instruction of rehab and technology aids (Cimarolli & Boehner, 2005)
* Poor information- may lead to overprotection
  * Families need to be educated
  * Associated with poor adjustment, depressive symptoms and decreased mastery of environment
    * (Cimarolli, Reinhardt & Horowitz, 2006)

****Families need information (education) and help on how to balance support and autonomy
Social support studies

- Studies found support of friends, family correlate to better outcomes
- Folks without support- may be institutionalized and decline in health
Social support (cont’)

- Support impacted by previous family functioning
- We need to be aware of that...
We often overlook family adjustment – efforts typically patient centered

We need to pay attention to family coping as it influences client’s coping and support

Screening needed for family adjustment and barriers to rehab

- Interview client and family separately
- Identify families with challenges
**FIGURE 6-1**

**Family Systems Framework: Emphasis on Family Interaction**

- **Inputs**
  - Family Characteristics
    * Characteristics of the family
    * Personal characteristics
    * Special challenges

- **Family Interaction**

- **Process**
  - Extended Family
  - Marital
  - Parental
  - Sibling

- **Family Life Cycle**
  - Development stages
  - Transitions

- **Outputs**
  - Family Functions
    * Affection
    * Self-esteem
    * Spiritual
    * Economics
  - Daily care
  - Socialization
  - Recreation
  - Education

Role of Rehab Team

- Mental health services for client and family (with specialized training in low vision)
- Family Advisory Councils
- Patient and Family Education
- PFCC Mentors
Role of Rehab Team

- Remember health literacy issues
- Provide education and information
Role of Rehab

- OT Role-
  - Look at how caregiving has impacted occupations of family members
  - Provide support and resources to family
  - Groups for families and clients
  - Teach IADL’s to navigate system
Future Research....

- Limited empirical studies on successful adaptations by family members of folks with low vision
- Need to identify unique needs and concerns of family members of persons with low vision
- Gender and cultural differences in support
- Research in interventions and community services

- The journey continues....
∗ LuLu’s Journey

∗ Marco – age 2
  ∗ Diagnosed with retinoblastoma and glaucoma
Marco and his family's journey
References: