



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

Elise Bloch, Ed.D., OT/L
Florida International University
&
Liudmilla Camejo Rojas, OTR



PFCC and Low Vision

- * **PFCC Definition and tenets**
- * **History and barriers**
- * **Low vision issues**
- * **Rehab recommendations**
- * **Future Directions**
- * **LuLu's journey with Marco**

Patient and Family-Centered Care

- * **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**

Institute of Medicine-Crossing the Quality Chasm: A New Health Care System for the 21st Century, 2001

- * **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's Recommendations

- * **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

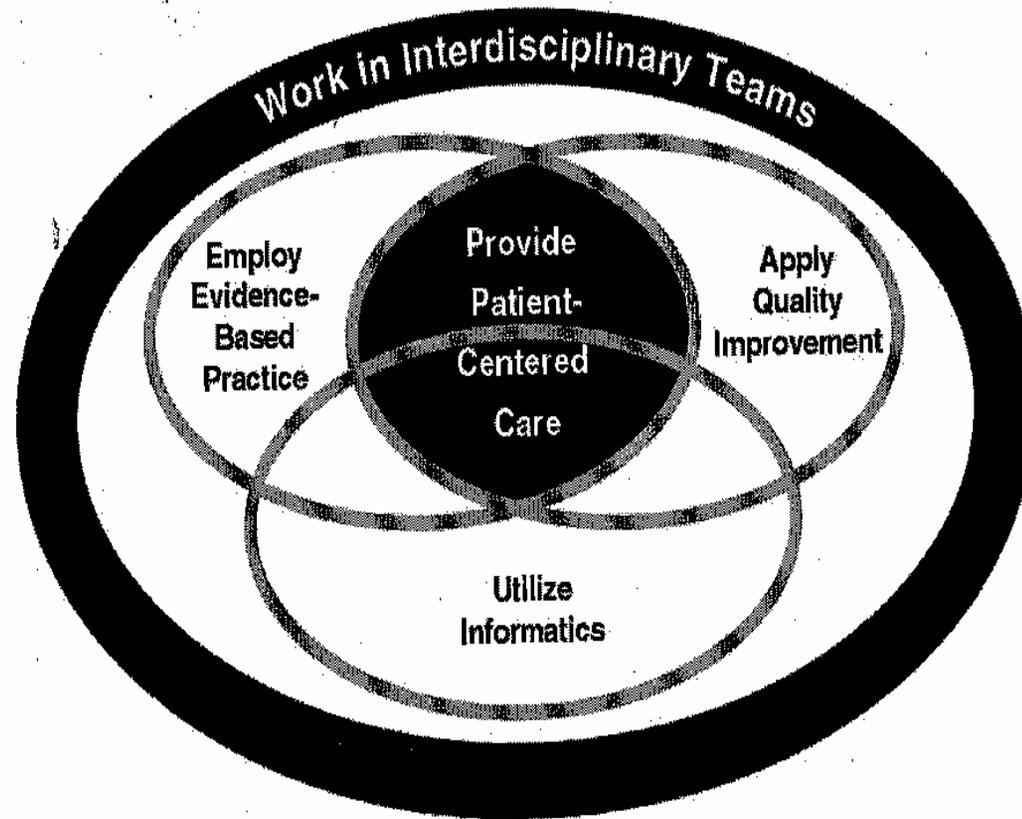


Figure 3-1 Relationship among core competencies for health professionals.

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**

PFCC and Low Vision Literature

- * **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)**

Instrumental Support Studies (-)

- * **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')

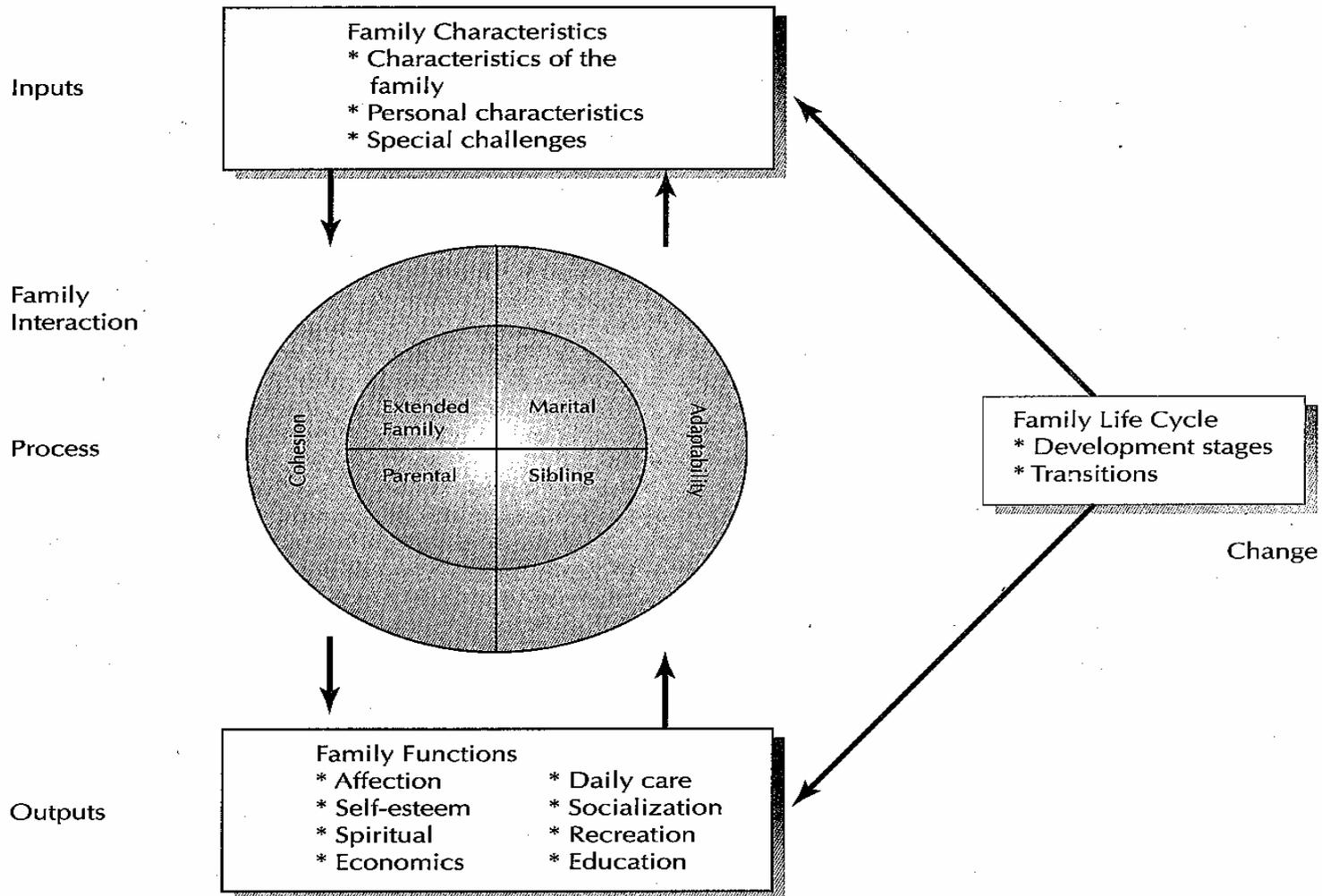
- * **Support impacted by previous family functioning**
- * **We need to be aware of that...**

Role of Rehab team

- * **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



Source: Turnbull, A. P., Summers, J. A., & Brotherson, M. J. (1984). *Working with families with disabled members: A family systems approach* (p. 60). Lawrence: University of Kansas, Kansas Affiliated Facility. Adapted by permission.

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



References:

- * **Cimarolli, V. R., & Boerner, K (2005). Social support and well-being in adults who are visually impaired. *Journal of Visual Impairment & Blindness*,99, 521-534.**
- * **Cimarolli, V., Reinhardt, J., & Horowitz, A (2006). Perceived overprotection: Support gone bad? *Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 61, 18-23.**
- * **Bambara, K., Jennifer, Wadley V., Owsley C., Martin R.C, Porter C , & Dreer L.,C (2009). Family Functioning and Low Vision: A Systematic Review *Journal of Visual Impairment & Blindness*, 137-146.**
- * **Turnbull A.P & Rutherford T (2004): *Families Professionals, and Exceptionality, Collaborating for Empowerment Merrill Prentice Hall New Jersey.***
- * **Greiner, C . A., & Knebel E : *Health Professions Education: Abridge to Quality Committee on the Health Professions Education Summit The National Academic Press Washington, DC (2003).***
- * **Institute Of Medicine Health. 2001a. *Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press.***