Patient and Family-Centered Care (PFCC)- Past, Present, Future

Elise Bloch, Ed.D., OT/L
Occupational Therapy Department, College of Nursing and Health Sciences, Florida International University
Lupe Collado, BS, COTA
Breakthrough Therapy Services

FOTA Conference Fall 2013
Objectives

- Understand historical context of PFCC
- Describe tenets of PFCC
- Describe legislative mandates that impact health care/education practice for OT
- Identify current practice trends
- Best practice models
- Role of OT’s in PFCC
Patient and Family-Centered Care

- Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in healthcare.

(Institute for Family-Centered Care, 2005)
PFCC Principles

▼ People are treated with respect and dignity.

▼ Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.

▼ Individuals and families build on their strengths through participation in experiences that enhance control and independence.

▼ Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery.
PFCC:

- PFCC acknowledges that we have an obligation to meet the 3 basic needs of the family:
  - The need for information
  - The need for reassurance/support
  - The need to be near the patient

(Henneman, 2002)
Leslie and Lupe’s Journey
Franklin’s Family Journey

- All T cell age 6 2002
- Relapsed age 8 BMT 2004

- Numerous iatrogenic effects of treatment continue
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
- PFCC- standard in pediatric world, moving over to adult
Public Perceptions of Health Care

▼ The system is a nightmare to navigate;
▼ Caregivers don’t provide enough information;
▼ Patients are not involved in decisions about their health care; and
▼ Hospital caregivers are not emotionally supportive.

(American Hospital Association and the Picker Institute, 1996)
Why Patient and Family-Centered Care?

- Social isolation is a risk factor.
- The majority of patients have some connection to family or natural support.
- Individuals, who are most dependent on hospital care, are most dependent on families...
  - The very young;
- The very old; and
- Those with chronic conditions.
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!
Joint Commission- and PFCC

- Patient Centered Communication Standards (2011)
  - The hospital effectively communicates with patients when providing care, treatment, and services.
  - The hospital respects, protects, and promotes patient rights.
    - The hospital allows a family member, friend, or other individual to be present with the patient for emotional support during the course of stay.
PFCC Education

- PFCC needs to be an integral part of academic and fieldwork training of health professionals

- Health Professionals typically not exposed to “PFCC”

- Training typically occurs in hospital that has commitment to PFCC
Institute of Medicine:
*Health Professions Education: A Bridge to Quality*

- IOM summit of interdisciplinary health professionals in 2002- designated core competencies to be integrated into health professions education.

- “All health professionals should be educated to deliver patient-centered care as members of an interdisciplinary team, emphasizing evidence-based practice, quality improvement approaches, and informatics.”

PFCC and Higher Education Curriculum

*Health Professions Education: A Bridge to Quality* (2003)
PFCC Agencies

- Institute for Family-Centered Care
- Picker Institute
- Planetree
PFCC today

- Standard of care in pediatric world-
  - Director of PFCC
  - Family Advisory Councils, Mentor Programs
  - PFCC behavioral objectives, hospital policies
  - Family and child input

- Model: CHOP, Cincinnati Children’s
- Joe DiMaggio Children’s Hospital
PFCC at Joe DiMaggio Children’s Hospital

- FAC and YAC
- Partner for design of new hospital
- PFCC Education to staff
- Collaborate on hospital committees
- Family rounding PICU and NICUs
- No “visitors’- partners in care, mentors – PFCC throughout MHS system
- Any hospital info for families goes thru FAC
PFCC today

- Adult world-
  - Dana Farber Medical Center
  - Calgary Hospital System
  - South Broward Hospital District
  - Washington Rehab Center
Family Faculty

- Family Faculty programs throughout the country are becoming “gold standards” to teach medical and allied health professionals about the experience of care.
- Personal stories of patients and their families moves beyond jargon and textbook instruction and goes to the heart of care.
- Listen.... Hear.......
Walk in our shoes....
CCU in Ca. implemented FCC program secondary to complaints from family members (low pt. and family satisfaction scores)

24 bed unit- combined ICU, CCU, ED - later become model of patient care throughout hospital.

Interdisciplinary team met every two weeks with medical director and nursing faculty member.
- Defined terms
- Identified what family and staff needed.
FCC and Critical Care
Damboise, Cardin (2003)

- Implementation-education sessions to nursing staff. 9 (2 hour sessions) over a 2 day period. A 2 hour class one month later for f/u. Monthly meeting after with nursing faculty.

- Changes- visitation policies more open and flexible, patient brochures, interdisciplinary family conferences, family presence during resuscitation, bereavement team formed.
<table>
<thead>
<tr>
<th>Variables</th>
<th>Before Family-Centered Care</th>
<th>After Family Centered Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of formal patient complaints to administration</td>
<td>12 (1999)</td>
<td>0 (2000)</td>
</tr>
<tr>
<td>Restraint use</td>
<td>11.81% (3/99-8/99)</td>
<td>5.56% (3/00-8/00)</td>
</tr>
<tr>
<td>Organ donations</td>
<td>40%</td>
<td>55%</td>
</tr>
<tr>
<td>Total ventilator hours</td>
<td>49,789 (YTD, 7/31/99)</td>
<td>34,318 (YTD 7/31/00)</td>
</tr>
<tr>
<td>Average ventilators/day</td>
<td>9.2 (YTD 7/31/99)</td>
<td>7.0 (YTD, 7/31/00)</td>
</tr>
<tr>
<td>Patient days</td>
<td>4,125 (YTD 7/31/99)</td>
<td>3,831 (YTD 7/31/00)</td>
</tr>
<tr>
<td>Average length of stay</td>
<td>2.59 days</td>
<td>2.39 days</td>
</tr>
<tr>
<td>Cost per patient stay</td>
<td>$638</td>
<td>$697/46*</td>
</tr>
</tbody>
</table>
| Nurses’ responses to: “Do you think the current visiting policy would meet YOUR needs if YOUR family member was a patient in the CCU?” | Yes = 42%  
No = 58% | Yes = 96%  
No = 4% |
| Letters received from families, naming individual nurses | 10 in 1 year (2/99-1/00)   | 37 in 6 months (2/00-7/00) |
| Patient care conferences              | 1 per month                | 4 per month                |
FCC & Maternal-Child Health-Capitulo & Silverberg(2002)

- Mt. Sinai in NYC- poor patient satisfaction in Women and Children’s Division
- Process began in 1995- created 3 care centers with 2 year reengineering process- with goal to improve quality of care.
- Focus groups of patients asking- what should we do that we should change? What do well that we should keep?
FCC & Maternal-Child Health-Capitulo & Silverberg(2002)

- Changes: maternity visiting hours open throughout the day to any one designated by patient to be sig. in their life, Breast feeding support.
- Peds wards- units redesigned from general to specific – resp/ hem-onc/cardiac-GI with primary nursing.
- Education-team building sessions, specialty training and fcc training.
FCC & Maternal-Child Health-Capitulo & Silverberg(2002)

- Outcomes- after 1 years patient complaint reduced 50%, complimentary letters rose over 100%
- Length of stay for pediatric asthma patients reduced 50% (attributed to staff enhanced expertise)
- Patient satisfaction went from 3.5 (5point scale) to 4.2 after implementation
FCC and NICU

- Developmental care, family-centered care (NIDCAP training) in NICU’s
- Fleisher et al. (1995) Working with families to support and teach them the development approach to care
- Outcomes - reduced need for gavage feedings, reduced need for positive airway pressure, decreased length of stay, decreased IVH’s, decreased hospital costs
FCC Summary

- FCC is “best practice” for patient care
- FCC makes sense
- FCC increases patient safety
- Nothing about you, without you!!!
Family Research Toolkit

What Is the Toolkit?

Our Beach Center Family Research Toolkit contains scales, surveys, checklists, and conversation guides we have developed in the course of our research. For each tool, we provide:

- A description of the purpose of the tool and what it measures
- A description of how we developed the tool and the psychometric properties, where relevant
- References and links to publications, current research, and other resources where the tool was used
- Links to allow you to request the tool or download it.

All our Beach Center Family Research tools are available free of charge. In some cases, we are asking you to request us to send you the tool because we want to keep track of how many others are using the tools and what they did with them.

Here are links to our current list of available tools:

- Beach Center Family Quality of Life Scale
- Family Quality of Life Conversation Guide
- Beach Center Family-Professional Partnership Scale
- Beach Center Family and Professional Self-Assessment Guide
- Beach Center Administrative Structures Surveys
- Beach Center Family Community Integration Survey
- Psychological Empowerment Survey
- Kansas Inventory of Parental Perceptions
Tool

Beach Center Family and Professional Partnership Self-Assessment Guide

General Description

The purpose of the Partnership Self-Assessment Guide is to assist professionals and parents to look at their practice and identify possible barriers and facilitators to their ability to have positive family-professional partnerships. Some examples of uses of the Self-Assessment guide are:

- As a tool to guide discussion and dialogue between parents and professionals.
- As a teaching guide for pre-service or in-service training, to develop strategies to enhance the quality of partnerships.

How It Was Developed

The Partnership Self-Assessment Guide is an outgrowth of the Beach Center Family-Professional Partnership Scale. For details on the development of the measure and its psychometric characteristics, see the Partnership Scale.

How to Get the Guide

The Partnership Self-Assessment Guide is available free of charge. Download and print your copy.

If you decide to use the Partnership Self-Assessment Guide, we would appreciate feedback, especially if you changed the format or used it in a different way. Please contact us at beachcenter@ku.edu with your comments and suggestions.
attitude or skill that the item represents. Also identify what hinders (gets in your way) of demonstrating the attitude or skill.

1. I help parents gain the skills or information to be able to get what their child needs (provide training to parents, help parents access information on resources).

<table>
<thead>
<tr>
<th>Score</th>
<th>What Helps</th>
<th>What Hinders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. As a professional, I have the skills to help children succeed (have basic competencies, engage in continuous learning to gain new information and skills, hold high expectations for the child’s achievement and provide meaningful opportunities for him or her to succeed).

<table>
<thead>
<tr>
<th>Score</th>
<th>What Helps</th>
<th>What Hinders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
About FCS Sheets

This series of 18 FCS Sheets provides information about family-centred service and strategies for using this approach. The FCS Sheets are written for parents, health professionals, and children’s rehabilitation organizations.

CanChild wishes to acknowledge the contribution of the team at CRDP Le Bouclier for their participation in the French translation of the FCS Sheets, specifically Lila Sorel, Dr. Bernard Michallet, Isabelle Meilleur, Martine Charron, Natalie Carpentier, and Stéphane Mercier.

FCS Sheets

FCS Sheet #1 - What is Family-Centred Service?
Aussi disponible en français / also available in French

FCS Sheet #2 - Myths about Family-Centred Service
Aussi disponible en français / also available in French

FCS Sheet #3 - How Does Family-Centred Service Make a Difference?
Aussi disponible en français / also available in French

FCS Sheet #4 - Becoming More Family-Centred
Aussi disponible en français / also available in French

FCS Sheet #5 - 10 Things You Can Do to Be More Family-Centred
Family-Centred Service: Resources

Family-Centred Service: A Best Practice Approach: In Brief

FCS Sheets

"Key Worker" Model of Service Delivery

PEGS: Results of a Validation Study: Project Reports

What Adolescents with Disabilities Want in Life: Keeping Current

What Helps and Hinders People at Turning Points: In Brief

What Makes Parents Satisfied with Rehab Service

Family-Centred Service: Measures

Canadian Occupational Performance Measure

Measure of Processes of Care (MPOC)

Measure of Processes of Care for Service Providers

Perceived Efficacy and Goal Setting (PEGS)
Inpatient Acute Rehabilitation Unit: 20 Bed, CARF Accredited Unit

Team approach with patient & family including:
- Physiatrist
- Occupational Therapist
- Physical Therapist
- Speech Language Pathologist
- Recreational Therapist
- Nurse
- Psychologist
- Rehabilitation Counselor
- Prosthetics and Orthotics
PFCC initiatives at UWRC

- Have PFCC advisory council since 2003
- PFCC Council members sit on hospital committees: ADA, safety
- Develop training programs for staff Staff competencies reflective of PFCC tenets
  Customer Satisfaction- Press Ganey Survey with 5 PFCC concepts
- Mission and vision statement
Original Job Summary

- **Job Summary:** Responsible for evaluation, planning, directing and administering occupational therapy evaluation and intervention to patients referred by a licensed provider. Administers treatments, training and physical agents as determined by the evaluation in an effort to restore function and prevent disability following injury, disease or physical disability. Evaluates and administers treatment for functional living skills such as self care, homemaking, range of motion, muscle testing, cognitive, visual perception, vocational and avocational skills, splinting, assistive technology and community integration. Reports data in both written and oral form following the policy and procedures of the OT department and the Medical Center. Provides supervision to less experienced therapists, students, COTAs, aides, and volunteers. Participates in the operational aspects of the department, maintains performance improvement activities within the department and participates in Quality Improvement activities. Follows procedures and standards for cost effectiveness. Ensures that patient charges are accurate and entered in a timely basis. Participates in all infection control, departmental equipment training, organizational safety and fire safety programs.
Patient/Family Centered Changes to the Job Summary

**Job Summary:** In collaboration with patients, families (as defined by the patient), and staff across disciplines and departments is responsible for evaluation, planning, directing and administering occupational therapy evaluation and intervention to patients referred by a licensed provider. Administers treatments, training and physical agents as determined by the evaluation in an effort to restore function and prevent further disability following injury, disease or physical disability. Partners with the patient and family and, considering the patient’s environment, evaluates and administers treatment for functional living skills such as self care, homemaking, range of motion, muscle testing, cognitive, visual perception, vocational and avocational skills, splinting, assistive technology and community integration. Reports data in both written and oral form following the policy and procedures of the OT department and the Medical Center. Provides supervision to COTAs, aides, and volunteers. Participates in operational aspects of the department, maintains performance improvement activities within the department and participates in Quality Improvement activities. Follows procedures and standards for cost effectiveness. Ensures that patient charges are accurate and entered in a timely basis. Participates in all infection control, departmental equipment training, organizational safety and fire safety programs.
OT and PFCC

- OT’s working on IADLS for children with chronic conditions
- Ie: Child with Type 2 Diabetes
  - Administer meds
  - Take insulin levels
  - Awareness of their health care needs
IADLS with Diabetes

Diabetes is a disease that doctors have known about for thousands of years.
IADLS and Med helper

- Teach kids to manage appts,
- Keep track of medical info
- Medications, allergies, docs-names and contact info
IADL’s with all kids

- What is an emergency?
- What to do?
- Where to go?
PFCC and OT

- Policy- be aware of PFCC issues and legislation –PCORI
- System level- FAC, include folks at all levels
- Individual level- facilitate autonomy and teach IADL to navigate health care system
PFCC Summary

- PFCC is “best practice” for patient care
- PFCC makes sense
- PFCC increases patient safety
- OT (client-centered) and PFCC is a natural fit!!!
- Nothing about you, without you!!!
References: