Family-Centered Care: From bench to bedside and back

Jos M. Latour RN, PhD
Nurse Scientist
Disclosure

No financial interest and
no conflict of interest to declare

Jos M. Latour

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Route to Knowledge

**Bench-to-Bedside**
Basic research first, but then adding clinical experience to bring ideas to patients

**Bedside-to-Bench**
‘nurse/physician-scientists’ — spending time primarily in the clinic but seek to do science

**Bench/Bedside to Bedside/Bench**
Few come from both ways aiming for a specific research niche

History Family-Centered Care

- Developed after World War II
- Changing social expectations for the care delivery
- Originate from US and UK
- Research “right time - right place”
  - Social readiness for change

History Family-Centered Care

Patient-Centered Care versus Family-Centered Care

Which came first, the chicken or the egg?
Family-Centered Care

- Aims for Quality Improvement:
  1. Safety
  2. Effectiveness
  3. Patient-Centred Care
  4. Timeless
  5. Efficiency
  6. Equity

Committee on Quality of Health Care in America, 2001
Crossing the Quality Chasm: A new health system for the 21st century
Family-Centered Care

Definition

The professional support of the child and family through a process of involvement, participation, and partnership, underpinned by empowerment and negotiation’ Smith et al. 2002

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 health care.

Institute for Patient- and Family-Centered Care, www.ipfcc.org
Principles of family-centered care are well-known but not consistently implemented into daily practice


What is family?

Needs-experiences as outcome variable

Minimal focus on satisfaction (and limitations)

Latour and Haines. Families in ICU: Do we truly consider their needs, experiences and satisfaction? Nurs Crit Care 2007:12;173-4
Bench / Bedside

Work across health care departments


Family-Centered Care

Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005

Judy E. Davidson, RN, FCCM; Karen Powers, MD; Kamyar M. Hedayat, MD; Mark Tieszen, MD, FCCM; Alexander A. Kon, MD, FCCM; Eric Shepard, MD, FCCM; Vicki Spuhler, RN, MS, CCRN; I. David Todres, MD, FCCM; Mitchell Levy, MD, FCCM; Juliana Barr, MD, FCCM; Raj Ghandi, MD, FCCM; Gregory Hirsch, MD; Deborah Armstrong, PharmD, FCCM

Crit Care Med 2007; 35:605-622

Objective: To develop clinical practice guidelines for support of patient and family in adult, pediatric, or neonatal patient-centered ICU
Family-Centered Care

- Decision-making
- Family Coping
- Staff stress related to family interaction
- Cultural support of family
- Spiritual and religious support
- Family visitation
- Family environment of care
- Family presence on rounds
- Family presence at resuscitation
- Palliative care

Families in European NICUs

Parents during Rounds

FACTS and MYTHS influencing Round Policies

ICU design: single rooms vs multiple bedded rooms
Length of time: presence has no effect on time
Privacy: Patients and ICU professionals
Teaching: Reduced teaching time
<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I like to be present for morning rounds.</td>
<td>90 (90)</td>
<td></td>
</tr>
<tr>
<td>My being present for rounds improves the care of my child.</td>
<td>72 (73)</td>
<td></td>
</tr>
<tr>
<td>It is helpful to hear the entire presentation and discussion of my child.</td>
<td>93 (93)</td>
<td></td>
</tr>
<tr>
<td>I am able to clearly understand the plan for the day during rounds.</td>
<td>76 (76)</td>
<td></td>
</tr>
<tr>
<td>I prefer for the plan to be conveyed to me by one individual after rounds.</td>
<td>32 (33)</td>
<td></td>
</tr>
<tr>
<td>I have confidence in the residents taking care of my child.</td>
<td>69 (70)</td>
<td></td>
</tr>
<tr>
<td>Being present for morning rounds gives me more confidence in the medical</td>
<td>74 (75)</td>
<td></td>
</tr>
<tr>
<td>care than if I was not present.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry that others will overhear information about me or my child during</td>
<td>5 (5)</td>
<td></td>
</tr>
<tr>
<td>round.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I arrange my day so that I can be present for rounds.</td>
<td>66 (67)</td>
<td></td>
</tr>
</tbody>
</table>
Family during Resuscitation

A European survey of critical care nurses’ attitudes and experiences of having family members present during cardiopulmonary resuscitation

P Fulbrook\textsuperscript{a,b,*}, J.W. Albarran\textsuperscript{b,*}, J.M. Latour\textsuperscript{c}


Family presence during CPR: A study of the experiences and opinions of Turkish critical care nurses

A Badır\textsuperscript{a,*}, D. Sepe\textsuperscript{b}


\textit{intensiv} 2007;15:294-298

Paediatric critical care nurses’ attitudes and experiences of parental presence during cardiopulmonary resuscitation: A European survey

P. Fulbrook\textsuperscript{a,b,*}, J.M. Latour\textsuperscript{c}, J.W. Albarran\textsuperscript{d}

The Presence of Family Members During Cardiopulmonary Resuscitation:

European federation of Critical Care Nursing associations, European Society of Paediatric and Neonatal Intensive Care and European Society of Cardiology
Council on Cardiovascular Nursing and Allied Professions
Joint Position Statement
Position statement

1. All patients have the right to have family members present during resuscitation.
2. The patient’s family members should be offered the opportunity to be present during resuscitation of a relative.
3. Support should be provided by an appropriately qualified healthcare professional whose responsibility is to care for family members witnessing cardiopulmonary resuscitation.
4. Professional counselling should be offered to family members who have witnessed a resuscitation event.
5. All members of the resuscitation team who were involved in a resuscitation attempt when family members were present should participate in team debriefing.
6. Family presence during resuscitation should be incorporated into the curricula of cardiopulmonary resuscitation training programmes.
7. All intensive and critical care units should have multi-disciplinary written guidelines on the presence of family members during cardiopulmonary resuscitation.
EURYDICE II Study

- Data collection: November 2009 to April 2010

- 409 consecutive children died in 45 PICUs
  (N/W Europe, n=351; C/E Europe, n=58)

- Overall median mortality rate was 4.3% (range 1-11.2%)

EURYDICE II Study

- 86% cases a staff meeting was organized to make the decision

- Physicians were the primary decision makers in all groups, with little involvement of the parents in the final decision

Decision Making process

Shared-decision model

Family's autonomy

Doctors' autonomy

- Family make the decision
- Family and physicians share the decision
- No decision is made
- Physicians make the decision

Bedside / Bench

Patient/Family satisfaction

- Politics
- Health care insurance
- Patient organisations
- Hospital management
- Medical/Nursing professions

Patient & Family Satisfaction = Quality Performance Indicator
Fig. 1. Framework for parent satisfaction in pediatric intensive care.

The EMPATHIC Study

Multi-center, descriptive, cross-sectional, psychometric, prospective cohort study to develop, test, and implement a parent satisfaction instrument

EMPATHIC = EMpowerment of PArents in THe Intensive Care
Explorations

### Table 1. Care items \((n=31)\) ranked by parents as more important than healthcare professionals

<table>
<thead>
<tr>
<th>Care Item</th>
<th>Parents (n=559)</th>
<th>Professional (n=264)</th>
<th>Cohen’s (d)</th>
<th>(P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents are informed about the (adverse) effects of the medication</td>
<td>(\bar{\mu} = 9.20), (\hat{\sigma} = 1.23)</td>
<td>(\bar{\mu} = 7.81), (\hat{\sigma} = 1.11)</td>
<td>(1.18)</td>
<td>(0.001)</td>
</tr>
<tr>
<td>The correct medication is given at the right time</td>
<td>(\bar{\mu} = 9.50), (\hat{\sigma} = 0.98)</td>
<td>(\bar{\mu} = 8.95), (\hat{\sigma} = 0.73)</td>
<td>(0.64)</td>
<td>(0.001)</td>
</tr>
</tbody>
</table>

Scoring scale was a 10 point scale: 1=completely unimportant to 10=extremely important; Ranking of items is based on Cohen’s \(d\) (unit weighted); \(\bar{\mu}\)=mean; \(\hat{\sigma}\)=standard deviation.

Table 3. Care items (n=25) parents find more important than NICU professionals. 1-6 point scale from ‘completely unimportant’ to ‘extremely important’

<table>
<thead>
<tr>
<th>Care items</th>
<th>Parents (n=148)</th>
<th>Professionals (n=81)</th>
<th>Cohen’s d</th>
<th>p (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents are informed about the (adverse) effects of the medication</td>
<td>5.52 ± 0.79</td>
<td>4.74 ± 0.85</td>
<td>0.95</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>The correct medication is given at the right time</td>
<td>5.84 ± 0.39</td>
<td>5.27 ± 0.61</td>
<td>1.14</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Moment of discharge is not influenced by bed capacity</td>
<td>5.38 ± 0.90</td>
<td>4.67 ± 0.89</td>
<td>0.79</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Caregivers stimulate parents to stay close to their child during procedures and tests</td>
<td>5.38 ± 0.84</td>
<td>4.91 ± 0.73</td>
<td>0.60</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Table 4. Descriptives, reliability estimates, and testing on domains of two cohorts

<table>
<thead>
<tr>
<th>Domains (statements)</th>
<th>Cohort 1 (n=667)</th>
<th>Cohort 2 (n=551)</th>
<th>Levene’s test differences on variances</th>
<th>T-test differences on means</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( \hat{\mu} )</td>
<td>( \hat{\sigma} )</td>
<td>( \alpha )</td>
<td>( \hat{\mu} )</td>
</tr>
<tr>
<td>Information (9)</td>
<td>5.32</td>
<td>0.72</td>
<td>0.84</td>
<td>5.33</td>
</tr>
<tr>
<td>Care &amp; Cure (30)</td>
<td>5.32</td>
<td>0.60</td>
<td>0.92</td>
<td>5.35</td>
</tr>
<tr>
<td>Parental Participation (8)</td>
<td>5.23</td>
<td>0.73</td>
<td>0.77</td>
<td>5.30</td>
</tr>
<tr>
<td>Organization (6)</td>
<td>5.42</td>
<td>0.63</td>
<td>0.73</td>
<td>5.47</td>
</tr>
<tr>
<td>Professional Attitude (12)</td>
<td>5.47</td>
<td>0.58</td>
<td>0.88</td>
<td>5.50</td>
</tr>
</tbody>
</table>

\( \hat{\mu} \)=mean; \( \hat{\sigma} \)=standard deviation; \( \alpha \)=Cronbach’s alpha on standardized items; P-value is two-tailed; Range of scoring scale was 1-6.

Table IV. Descriptives, reliability estimates, and testing on domains of two cohorts

<table>
<thead>
<tr>
<th>Domains (statements)</th>
<th>Cohort 1 (n=220)</th>
<th>Cohort 2 (n=59)</th>
<th>Levene’s test differences on variances</th>
<th>T-test differences on means</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>mean  SD  α</td>
<td>mean  SD  α</td>
<td>F  p</td>
<td>t  p</td>
</tr>
<tr>
<td>Information (12)</td>
<td>5.26  0.69  0.86</td>
<td>5.22  0.68  0.85</td>
<td>0.18  0.67</td>
<td>0.28  0.78</td>
</tr>
<tr>
<td>Care &amp; Treatment (17)</td>
<td>5.45  0.57  0.91</td>
<td>5.53  0.60  0.95</td>
<td>0.12  0.73</td>
<td>-0.97  0.33</td>
</tr>
<tr>
<td>Parental Participation (8)</td>
<td>5.32  0.78  0.85</td>
<td>5.36  0.85  0.91</td>
<td>0.02  0.90</td>
<td>-0.33  0.74</td>
</tr>
<tr>
<td>Organization (8)</td>
<td>5.37  0.61  0.82</td>
<td>5.45  0.57  0.84</td>
<td>0.52  0.47</td>
<td>-0.90  0.37</td>
</tr>
<tr>
<td>Professional Attitude (12)</td>
<td>5.50  0.58  0.90</td>
<td>5.57  0.55  0.92</td>
<td>0.36  0.55</td>
<td>-0.80  0.43</td>
</tr>
</tbody>
</table>

α=Cronbach’s α on standardized items as a measure of consistency;

p-value is two-tailed;

Item scoring range 1-6.

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Outcome

High ratings given to satisfaction items

But… items below our established standard

- Daily consultation with physician
- Discharge planning
- Noise levels and IC-bed space
- Involvement in decision-making on care and treatment
- Differences in information provision by nurses and physicians
- Assigning a primary nurse
Latour JM. Empowerment of parents in the intensive care. 2011
Summary

- Bench needed
  but with input from the bedside

- Individual patient and family care
  but with knowledge of their needs

- Training of intellectual intelligence
  but also social intelligence - empathy
Thank You
Jos Latour

j.latour@erasmusmc.nl

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