Family presence in paediatric and neonatal area

PNAE Meeting, Amsterdam, November 8th - 9th 2012

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Unit for Professional Development, Continuous Education and Nursing Research- Health Direction

IRCCS Bambino Gesù Children’s Hospital- Italy
Objectives of this presentation:

1) Exploring the concept of family centered care and its evolution
2) Discussing about Child and family centered Care
3) Focusing about Functional vs Holistic approach
4) Describing the issue of the family presence in the different settings
5) Delineating the organizational and educational prerequisite for family presence both in neonatal and in pediatric setting
From the beginning...

→ the child- when the parents weren’t in the wards yet

→ the child-mother unit, when the mother was permitted to stay in the units near the child
The change during the time ...

→ the child-parents unit when the fathers were permitted to stay in hospital were involved in the care, too

→ the family centered care, when health providers recognize the family as a resource for the child especially when ill
But we could forget someone ???

The children express desire for consultation and information to enable them to understand their illness; in preparation for procedures; and to be involved in a decision making process. (Coyne 2006)
Still ...

It is an imperative that nurses use consistent, structured and robust methods and more explicit criteria to determine children’s involvement in decision making ensuring that it is in their best interest (Coleman 2010)

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Not only theoretical, but it is also a formal change ...

**From:** NHS- The patient’s Charter: Service for Children and Young People (Department of Health 1996) stated the families’ right and expectation to be involved in the child’s care both in hospital or community setting.

**To:** (UK) National Service Framework for Children, Young People and Maternity Service in England (Department of Health 2004) → child-centred care as opposed to family centred care.

(USA) Institute of Family Centered care “patient and family centered care”
Not only theoretical, but it is also a formal change ...

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.

Patient- and family-centered 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 that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them.

Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction

Website Consultation on 2-11-12 http://www.fv-ncfpp.org/quality-health-care1/family-centered-care/

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Not only theoretical, but it is also a formal change ...

The focus has been primarily on the partnerships between patients, families, and providers at the clinical level.

There has been far less attention paid to the effect of patient and family advisors and leaders at the program and policy level on quality and safety.

However, as more health care organizations engage patients and families as advisors and leaders, we have seen an increase in efforts to evaluate these collaborative endeavors.

Website Consultation on 2-11-12  http://www.fv-ncfpp.org/quality-health-care1/family-centered-care/
FCC the theoretical frameworks

**Functional**
- Family seen in its normal context
- Risk of lack of collaboration
- Focused on the performance of usual childcare practices to be continued in hospital
- Focused on family problems and weakness
- The power remains with the nurse as a gatekeeper
- The families may be disempowered

Nethercpott 1993- initially developed in acute care settings- Britain

**Holistic**
- Family as the constant in the child's life/supportive services as fluctuating
- Collaborative model at all levels of care
- Meets the diverse needs of families and respects different ways of coping
- Explores families strengths
- Family to family support and networking
- Nurse as partner empowering family and children

Shelton and Smith Stephanek 1995- developed for children and families with special needs- USA

**Parental role**

**Family empowerment**

*Smith, Coleman and Bradshaw. Family centred* 2010

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FCC the theoretical frameworks

Functional versus Holistic

Are these two, opposite concepts???

- The nurse haven’t time do feed the child
- The mother experiments self efficacy in feeding her child

The input could be functional or holistic, but perhaps the final result is really important: the involvement in the care and the mother feeling

Parental role

Family empowerment

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And now discuss together about family presence!!!

Considering for example:
- the different cultures,
- the different resources,
- the different spaces
Family presence: always and every where???

<table>
<thead>
<tr>
<th>location</th>
<th>When in the day</th>
<th>Who and How many persons of family</th>
<th>Special facilities in the ward</th>
</tr>
</thead>
<tbody>
<tr>
<td>General pediatric area</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>PICU</td>
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<tr>
<td>I level Infants</td>
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<tr>
<td>NICU</td>
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<tr>
<td>Adolescent</td>
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<tr>
<td>Psychiatric area</td>
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</table>

Family presence in paediatric and neonatal area

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### Family presence: during procedures ???

<table>
<thead>
<tr>
<th>Location</th>
<th>YES/NOT</th>
<th>Who and How many of family</th>
<th>To do something?</th>
<th>Special strategies to assist the family/health provider</th>
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## Family presence: during invasive procedures

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<tr>
<td>Level 1 Infants</td>
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<td>NICU</td>
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**CFCC: Why the presence??** It’s the pre-requisite of a practice continuum

<table>
<thead>
<tr>
<th></th>
<th>No involvement</th>
<th>Involvement</th>
<th>Participation</th>
<th>Partnership</th>
<th>Parent-led</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Nurse-led</td>
<td>Nurse-led</td>
<td>Nurse-led</td>
<td>Equal status</td>
<td>Parent-led</td>
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<tr>
<td>NURSE</td>
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*Smith, Coleman and Bradshaw. Family centred care. 2002*

Family presence in paediatric and neonatal area

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Presence of the Family: some news from the literature

Presence in Neonatal area

Abstract

Objective: To describe policies towards family visiting in Neonatal Intensive Care Units (NICU) and compare findings with those of a survey carried out 10 years earlier.

Methods: A questionnaire on early developmental care practices was mailed to 362 units in eight European countries (Sweden, Denmark, the UK, the Netherlands, Belgium, France, Spain and Italy). Of them 78% responded, and among those responded, 175 reported caring for at least 50 very low birth weight infants every year and their responses were analysed further.

Results: A majority of all units allowed access at any time for both parents. This was almost universal in northern Europe and the UK, whereas it was the policy of less than one-third of NICU in Spain and Italy, with France in an intermediate position. Restrictions on visiting of grandparents, siblings and friends, as well as restricting parents’ presence during medical rounds and procedures followed the same pattern. A composite visiting score was computed using all the variables related to family visiting. Lower median values and larger variability were obtained for the southern countries, indicating more restrictive attitudes and lack of national policy.

Conclusions: The presence of parents and other family members in European NICUs has improved over a 10-year period. Several barriers, however, are still in place, particularly in the South European countries.
Presence of the Family: some news from the literature

Presence in Neonatal area

**Abstract**

Aim: To compare individual room implemented family-centred care to classical designed neonatal intensive care unit and find out its effect on rehospitalization and application to health services in preterm infants after discharge.

Methods: Mothers whose infants were born before 34 gestational weeks and hospitalized for at least one week in the NICU were enrolled in the study. Mothers who were hospitalized with their preterm infants in individual rooms (Group I) were compared with mothers who were not hospitalized with their preterm infants (Group II). After the third postdischarge month, groups were compared for their rates of phone consultations to physician/hospital, acute care applications, rehospitalization and parent’s perception of child's vulnerability.

Results: Although demographic and medical information did not indicate any differences between the groups, the mean number of acute care visits (p = 0.046), the median number of phone consultations (p = 0.001) and rehospitalization rate (12.9% vs. 34.5%, p < 0.05) were significantly higher in Group II. The anatomical problems, such as inguinal hernia and retinopathy of prematurity, were the main recorded causes in Group I whereas problems related to prematurity like feeding difficulties were dominating in Group II.

Conclusion: The availability of individual rooms that allows maternal presence and participation during the hospitalization of the mother’s preterm infant, is correlated with lower rates of rehospitalization and healthcare applications.
Presence of the Family: some news from the literature

Presence in Intensive Pediatric Area

Parental presence and visiting policies in Italian pediatric intensive care units: A national survey*

**Objective:** To investigate parental presence and visiting policies in Italian pediatric intensive care units (PICUs).

**Design:** Descriptive survey.

**Setting:** All 34 Italian PICUs.

**Patients:** Patients were not involved in this work.

**Interventions:** None.

**Measurements and Main Results:** A questionnaire was sent to the unit heads. Response rate was 100%. Median daily visiting time for parents was 300 mins; for other visitors, it was 120 mins. Twelve percent of PICUs had unrestricted policies; 59% did not allow the constant presence of a parent, even during the day. Visits from other relatives and from nonfamily were not permitted in 35% and 88% of units, respectively. Policies were not modified for a dying patient in 6% of PICUs. Children’s visits were not allowed in 76% of units. Cardiac surgical PICUs were more likely to have restrictive visiting hours. Parents were permitted to be present at the bedside during ordinary nursing procedures, invasive procedures or cardiopulmonary resuscitation in 62%, 3%, and 9% of PICUs, respectively. No waiting room was provided in 32% of PICUs. Gowning procedures were compulsory for visitors in 94% of units. In 48% of PICUs, a formal process of revising visiting policies was ongoing. On patient admission, 77% of PICUs provided the family with informative material on the unit. Phone information on the patient was given frequently (often/always, 70% of PICUs).

**Conclusions:** In Italian PICUs, there is a marked tendency to apply restrictive visiting policies, not to allow parents 24-hr access at bedside, and to limit the presence of parents during procedures and cardiopulmonary resuscitation. A revision of current policies has begun, signaling a readiness for change. (Pediatr Crit Care Med 2011; 12:e46–e50)

**Key Words:** pediatric intensive care; visiting policies; parents; family; waiting room; gowning procedure
Presence of the Family: some news from the literature

Presence in Intensive Pediatric Area

OBJECTIVES: Our objectives were to determine the impact of family presence during PICU rounds on family satisfaction, resident teaching, and length of rounds and to assess factors associated with family satisfaction.

METHODS: This was an observational study of a convenience sample of morning work rounds in a PICU, followed by surveys of family members of patients in the unit and residents who had been present for rounds.

RESULTS: A total of 411 patient encounters were observed, 98 family questionnaires were fully completed, and 33 resident questionnaires were completed. Ninety-eight percent of family members liked to be present for rounds. On the first day of admission, family members were less likely to understand the plan ($P = .03$), to feel comfortable asking questions ($P = .007$), or to want bad news during rounds ($P = .009$). They were more likely to have privacy concerns ($P = .02$) and to want 1 individual to convey the plan after rounds ($P = .01$). Higher education level was associated with decreased privacy concerns ($P = .002$) but did not affect understanding of the plan. Fifty-two percent of residents perceived that teaching was decreased with families present. Time spent with individual patients was not increased by family member presence ($P = .12$).

CONCLUSIONS: Family satisfaction is high, but families of patients on the first day of admission may need special attention. The medical team should conduct rounds in a manner that addresses the privacy concerns of families. Residents often think that teaching is decreased when families are present. *Pediatrics* 2009;124:1119–1125

Impact of Family Presence During Pediatric Intensive Care Unit Rounds on the Family and Medical Team

AUTHORS: Paul L. Aronson, MD,*b Jennifer Yau, MBS,*c Mark A. Helfaer, MD,*d and Wynne Morrison, MD,*d

WHAT'S KNOWN ON THIS SUBJECT: Family members prefer bedside rounds and feel more informed when they are present for rounds.

WHAT THIS STUDY ADDS: This study is the first to show that families on the first day of admission have different preferences for family-centered rounds than do families later in admission. Family presence does not affect the length of rounds.
CONCLUSIONS: Children surviving pediatric intensive care unit have significant adaptive behavior functioning and functional morbidity and reduced health-related quality of life. Although neurologic morbidity following intensive care unit was associated with baseline state, we found that severity factors were independently associated with the development of acquired brain injury and reduced
Family centered care

- Specific institutional policies for the family
- Adequate living conditions for families
- Continuing education for health provider to guarantee high level of competences and knowledge (including relational competences)
- Support programs for families, health providers and the promotion of peer support
- Personalized care
- Effective resource planning to guarantee enough time for family education and support within nursing care
- Requiring documentation of patient information and education provided
- Shared rules of behaviour in hospital (e.g. hygiene, privacy)
PARTNERING WITH PATIENTS AND FAMILIES TO DESIGN A PATIENT- AND FAMILY-CENTERED HEALTH CARE SYSTEM

Recommendations and Promising Practices

April 2008

Institute for Family-Centered Care
www.familycenteredcare.org

Family centered care, the policy

The paper also defined the following four core concepts of patient- and family-centered care:

- **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- **Collaboration.** Patients, families, health care practitioners, and hospital leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

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Child and Family centered care
the policy for presence

- At European level
- At National level
- At local level

The importance of the
Patients/family
Associations
A proposal for PNAE survey:

Child and Family centered care the policies for presence

- At European level
- At National level
- At local level

Family presence in paediatric and neonatal area

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Conclusions

Thank you