Family Centered Care: Aiming for Excellence
Exploring the Past, Present, and Future.

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IMAGINE
“IS NOT A SINGULAR INTERVENTION BUT RATHER A PHILOSOPHICAL APPROACH TO CARE THAT RECOGNIZES THE NEEDS OF PATIENTS’ FAMILY MEMBERS”.

(Henneman & Cardin, 2002)
“is a partnership approach to health care decision-making between the family and health care provider”.

(Kuo et al., Maternal Child Heath, 2012)
Common words

- Partnership
- Collaboration
- Information sharing
- Respect
- Negotiation
- empowering
Family Defined

- The word "family" refers to two or more persons who are related in any way—biologically, legally, or emotionally. Patients and families define their families.

- Institute for Patient and Family Centered Care, 2014.
Why Family-Centered Care

• All patients will be accompanied by a distressed family beginning to experience psychological and social alterations due to their loved ones admission

• Beginning crisis, experiencing such phenomenon as “role alterations, uncertainty, loss of control, being in an unfamiliar environment, financial constraints, and fear of loss” (Holden et al., 2002)

• A Task force for The Society of Critical Care Medicine has coined the term, POST INTENSIVE CARE SYNDROME-FAMILY (PICS-F) to explain the cluster of complications that families experience (Critical Care Medicine, 2012)
Benefits of Providing Family Centered Care

• Family’s feel less anxious
• Are the voice of the patient
• Families are the single greatest institution that influences a person’s health. *Friedman et al., 2003*
• lengths of hospital stays were shorter and re-hospitalizations were fewer. *Forsythe, P. 1998.*
Family centered Care

WONDERFUL PLAN AND IDEA

BUT

• Needs clear standards and guidelines to operationalize through
  • PRACTICE
  • EDUATION
  • POLICY
  • LEADERSHIP
The Past
The Past
Family defined
Patients have families, 1945
Patients have Families by Henry Richardson, M.D.

“Patients Have families: hospitals have patients: therefore the hospital has something to do with the family”

“only at one hour in the twenty-four is there any substantial evidence that friends and relatives of the patient really do exist, and this is during the time which is allotted to visitors”
1960 -

• Critical Care units began to develop
“...if a nurse expands her concept of the patient from that of an individual in a bed to that of a participating member of a family, then she will expand her role to assist relatives to cope with the patient’s illness while simultaneously maintaining family function”

Craven, R. 1972, Nurse Forum
First Children hospital in US
Molter, 1979

- 5 NEEDS of Families – in critical care environment

- Information
- Support
- Proximity
- Assurance
- Comfort

- Multiple studies investigating
The top 10 Needs – based on 11 CCFNI studies (1986-2002)

• To know the prognosis
• To have questioned answered honestly
• To be called at home if any changes occur
• To be assured the best possible care if given
• To know the facts concerning patient progress
• To receive information about the patient once per day
• To feel there is hope
• To feel hospital personnel care about the patient
• That explanations are in understandable terms
• To know the patient is being treated medically
PAST

The Doctor

The Health Care institute

Other Health care team members

The Patient

The Nurse

THE FAMILY
The Present
“I am sorry you can’t come in, it’s shift change.”
The trust relationship
Practice

• 78% of ICU nurses in adult critical care units prefer unrestricted visiting policies yet, 70% of hospital ICU’s restrict family visitation (AACN practice alert)

• Children are restricted from visitation (AACN practice alert)
Family Visitation – a good trend

- In 2008/2009 about 75% of all hospital and 90 percent of ICU’s in the US restricted visiting in some fashion according to a study of 606 hospitals. *Critical Care, 2013.*

- The American Hospital Association research conducted this year, 2014 found 42% of hospitals in US reported restricted visiting hours
Family Visitation

- In Canada, no detailed tracking of hospitals doing away with visiting hours.
  - Island Health, Vancouver Island, BC – made the change a few years ago
  - Quinte Health Care, Belleville, ON – network of 4 hospitals, October 2013
  - Providence Heath Care, Vancouver BC – network of 16 facilities in December 2013
  - Kingston General Hospital –2010, offering families Cots in ICU

- In a casual survey of hospitals in our lower mainland 2014,
<table>
<thead>
<tr>
<th>Where</th>
<th>unit</th>
<th>Type</th>
<th>Limit on families visiting at one time</th>
<th>Restricted visiting times?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Island Health</td>
<td>Cardiovascular</td>
<td>adult</td>
<td>Usually 2 but flex</td>
<td>Not during shift change but don’t turn them away</td>
</tr>
<tr>
<td>VGH</td>
<td>ICU</td>
<td>adult</td>
<td>2</td>
<td>Shift change and rounds</td>
</tr>
<tr>
<td>St. Pauls</td>
<td>Csicu</td>
<td>Adult</td>
<td>2</td>
<td>Shift change</td>
</tr>
<tr>
<td>RCH</td>
<td>ICU</td>
<td>Adult</td>
<td>2</td>
<td>Shifts change</td>
</tr>
<tr>
<td>SMH</td>
<td>icu</td>
<td>Adult</td>
<td>Not usually depende on Nurse</td>
<td>Shift change</td>
</tr>
<tr>
<td>CGH</td>
<td>Icu</td>
<td>Adult</td>
<td>Not usually dependent on nurse</td>
<td>Shift change</td>
</tr>
<tr>
<td>St Pauls</td>
<td>Icu</td>
<td>Adult</td>
<td>2</td>
<td>Shifts change</td>
</tr>
<tr>
<td>BC children</td>
<td>Icu</td>
<td>Neonates</td>
<td>Parents - no, all other, yes</td>
<td>None</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Couch? Cot?</th>
<th>Rounds participation</th>
<th>Participate in care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quiet room next door</td>
<td>yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No, waiting room</td>
<td>No</td>
<td>Nurse dependent</td>
</tr>
<tr>
<td>Waiting room has couches</td>
<td>No</td>
<td>Nurse dependent</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
<td>Yes, nurse dependent</td>
</tr>
<tr>
<td>Yes couches at bedside</td>
<td>no</td>
<td>Yes</td>
</tr>
<tr>
<td>Waiting room couch</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Couches waiting room</td>
<td>Rarely</td>
<td>Nurse dependent</td>
</tr>
<tr>
<td>Waiting room, but 2 family/babe rooms for crisis</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
family – open visitation

• Benefits
  • Less med errors
  • Families less angry
  • Increased safety
  • Family thankful
  • Consistency between staff – everyone can come in

• Challenges
  • Shifts in unit cultures
  • Increased risk of infection, no evidence to support
  • Small rooms – in older hospitals – crowded
  • Disrupt other patients
  • Unnecessary pressure on nurses and staff
  • privacy
Trending

- Family area in CC room
- Don’t need to call in to visit

- Code Help – Vancouver based program – possibly first of its kind in Canada

- Participate in rounds?
- Participate in care?
trending
Children’s hospitals

• Mid 20\textsuperscript{th} century – child/family separation trauma in the inpatient setting recognized and hospital policies were altered to allow rooming in, extended visiting hours, sibling visits
• The AAP recommended that conducting attending physician rounds (ie. patient presentations and rounds discussions) in the patients’ rooms with the family present should be standard practice.

Challenging current practice

• “They can come in but I have no time for them”
• “I updated them but they don’t understand”
Caution

• Family presence alone is considered insufficient, as family members must participate in the discussion and decision-making.
Family Assessment tools

- Calgary family assessment tool 15 minute
- And others

**LEGO PAIN ASSESSMENT TOOL**

- **NO PAIN**
  - Alert smiling
  - No humor
  - Eyes open

- **MILD PAIN**
  - No pain
  - Can be ignored
  - Eyes open

- **MODERATE PAIN**
  - Frown
  - Slight tear
  - Interferes with tasks

- **SERIOUS PAIN**
  - Intense stare
  - Grimace
  - Interferes with concentration

- **SEVERE PAIN**
  - Bulging eyes
  - Audible screams
  - Palpable pain

- **WORST PAIN POSSIBLE**
  - Agonizing screams
  - Face twisted beyond recognition

Created by Brendan Powell Smith. www.TheBlack Testament.com. This chart is not sponsored, authorized, or endorsed by the LEGO Group.
Institutions

• Institute for Patient and Family Centered Care (PFCC)

• Canadian Foundation for Healthcare Improvement (CFHI)

• Hospital based
• PFCC Innovation Center, Patient and Family Methodology and Practice – University of Pittsburgh Medical Center – it is an applied research center
The Institute for Patient- and Family-Centered Care, a non-profit organization founded in 1992, takes pride in providing essential leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, the Institute facilitates patient- and family-centered change in all settings where individuals and families receive care and support.

- The Institute also serves as a central resource for policy makers, administrators, program planners, direct service providers, educators, design professionals, and patient and family leaders.
- Nationally and internationally recognized for leadership in promoting organizational change
Institute of patient and family centered care

- CORE CONCEPTS
- DIGNITY AND RESPECT
- INFORMATION SHARING
- PARTICIPATION
- COLLABORATION

- Provides Resources for practice and policy
  - Changing the Concept of Families as Visitors: Supporting Family Presence and Participation
  - Patient- and Family-Centered Adult Intensive Care: A Self-Assessment Inventory
  - Patient and Family Centered care: A hospital self assessment inventory
  - And many more
Canadian Foundation for healthcare Improvement, CFHI

• For more than a decade, the Canadian Foundation for Healthcare Improvement, or CFHI, has been dedicated to accelerating healthcare improvement in Canada.

• We are a not-for-profit organization – funded by the Government of Canada – with collaborations across the country that include partnerships with researchers, practice leaders and front-line clinical leaders. Since our inception in the late 1990s, we have established a pan-Canadian reach and built an international reputation.

• We collaborate with decision-makers to tackle difficult questions about how to organize, finance, manage and deliver high-quality, affordable, patient- and family-centered healthcare for Canadians. We are confident that by working with partners we can reshape healthcare in Canada to improve its quality and results. That’s why we work at the nexus of health policy and delivery—the point where meaningful breakthroughs happen with direct benefits to patients.
Education

• At BCIT – part of the CC program. Module written on it

• At PFCC 6th international conference – Educational app created and worked on for new residences.
Current Family text examples

**Family Nursing as Relational Inquiry**
Developing Health-Promoting Practice
Gweneth Hartrick Doane
Colleen Varcoe

**Nurses and Families**
A Guide to Family Assessment and Intervention
Lorraine M. Wright
Maureen Leahey
POLICY

• In France, study done on 222 adult and 41 pediatric ICU’s. Only in 7% of the adult ICU’s did a 24 hour visiting policy exist. (Lavergne et al. 2011. Journal of Clinical Nursing)

• CACCN Position statement, 2005

• AACCN, 2011

• The Society of Critical Care medicine, 2007

• In BC, excellent book in fraser health authority, Patient and family centred care in critical care
Research – so many + reasons for Family Centered Care

• Involving family in care – beneficial - mitchell, 2012
• Family experiences of waiting rooms. Kutash and Northrop, 2007
• Meeting the needs. Davidson, 2009 (and many others)
• Perceived and unmet need – Jordanian family. Omari, 2009
• Family presence during resus, McClement, et al. 2009
• FCC: concept analysis. Hutchfield, 1998

• AACN – Practice alert : Family presence in the adult ICU – has 51 references
PRESENT

Other Health care team members

The Doctor

The Nurse

THE PATIENT

The Health Care institute

THE FAMILY
The Future
HI, you must be Sue. We’ve been waiting for you.
FCC in the future

• Although the importance of the role of the patient’s family is recognized in most areas of health care, integration of the family into the unit of care has not been widely explored in adult critical care. Mitchell et al. 2009
Practice
Policy
Institutions
Research
Education
Strategies/PRACTICE to support FCC – requires POLICY

- Free parking for long term patients
- Pager system for contact
- Overnight sleeping areas
- Family conference room – rename Care Conference
- Increased family presence - open visiting hours
- Surgery to ICU communication enhanced
- Normalizing agents – toiletries, cell phone charges, snacks
- Family website or Family APP
- Pt/family information – handouts?
- Standardizing uniforms – name tags (first name and occupation)
- Introduce yourself
FCC – change for the future

• FCC invokes a culture shift in attitude and the way clinical care is delivered. Families as partners challenges the care paradigm of unilateral responsibility for decision making.

• Kuo et al., 2012, Maternal Child Health
EDUCATION – FOR ALL

- In educational institutions
- In hospitals
- FOR FAMILIES

EDUCATION BEFORE IMPLEMENTATION
Ensure proper education- the groundwork to success
RESEARCH

• The Estonia NICU pilot project

• Continued research to help guide hospitals, health systems and policy makers (Kuo et al, 2012)
Moving Forward
powerful resource - family

• Creating patient and family advisory councils, whose members weighs in on nearly every decision a hospital makes
• Asking former patients to help design learning materials and signage for the hospital
• Inviting patients to sit on hiring panels for hospital staff
• Hosting town hall style meetings at which patients and their families can raise concerns about the hospital
The Future

- All health care members orientation – family presence
- Family presence on interview process
- **A family BUNDLE** – Like the sepsis bundle etc.
- Family at rounds
- **CREATE AN APP FOR** staff about FCC IN ICU
  - GETTING SHIFT REPORT WITH A FAMILY PRESENCE
  - DOING AN ASSESSMENT WITH FAMILY PRESENCE
  - TALKING TO THE FAMILY
  - HOW TO TALK TO THE FAMILY DURING A CRISIS
  - HOW TO EDUCATE THE FAMILY
  - HOW TO ANSWER QUESTIONS IN APPROPRIATE LANGUAGE
  - INVITING THE FAMILY TO PARTICIPATE IN ROUNDS AND CARE
- **FAMILY SUPPORT GROUPS**
- **FCNS** or Family Liaison
Moving Forward

• DISCUSS
• CHALLENGE
• INVITE
• PARTICIPATE
• INCREASE AWARENESS
• DON’T AGREE WITH STATUS QUO

• TALK ABOUT FCC

• Pick one strategy from the list and implement it.
PATIENT AND FAMILIES ARE THE MOST UNTAPPED RESOURCE IN HEALTH CARE