Research Challenges with Families in Crisis

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May 15, 2013
Building Bridges to Nursing Research Conference
Objectives

• Describe methodological research challenges
• Provide overview of key learnings from “Effects of Family Presence During Resuscitation after Trauma” and “Quiet Time for Nonverbal Patients in the MICU”
• Collaboratively brainstorm techniques and strategies
How many of you...

- Work in the ICU?
- Take care of nonverbal/non-decisional patients?
- Have ever obtained consent for a research study?
- Have enrolled a non-decisional patient in a study with consent from a family member?
Background

- Majority of patients in the ICU are not decisional
  - 5% of patients can make decisions
- Families serve as surrogate decision makers
- Critical Illness = Family Crisis

Carlet et al., 2004
What does the literature say?

• Prospective, multicenter study in 10 French ICUs
• How often do surrogates decisions reflect patient wishes?
• 2 hypothetical studies
  – Low risk (plasma expanders in septic shock)
    • 79% of patients said yes and 15% said no
    • 68% of surrogates said yes and 16% said no
    • 32% Discrepancy rate ($p = .01$)
  – High risk (early tracheostomy)
    • 49% of patients said yes and 41% said no
    • 46% of surrogates said yes and 36% said no
    • 42% discrepancy rate ($p = 0.0001$)

* Surrogates underestimate patients’ wishes to consent

Ciroldi et al., 2007
What else do we know?

- Some evidence that patients are more willing to participate when emergency care is needed

  - 12 stroke patients were interviewed and 10 out of 12 patients were willing to participate in research if a second stroke occurred.

  Blixen & Agich (2005)
Surrogate decision makers

- Interviewed patients who were not able to make decisions at the time of their stroke
- 9 out of 12 wanted family member to give consent for their research participation
- Had confidence in decision makers

Blixen & Agich (2005)
Defining family?

- Definitions can be too broad or narrow
- Biological family members aren’t always who the patient defines as family
- Family focused research - data from multiple family members
- Family related research – data from a representative family member
  - Single family informant
  - Better for recruitment

McClement & Woodgate, 1998
Families in Crisis

• Crisis theory – goal is to maintain emotional stability and balance
  – Constant internal and external stressors
  – An event occurs = emotional imbalance (hospitalization)
  – Coping is reduced
  – Crisis is time limited

Caplan, 1964; Leon & Knapp, 2008
Family Crisis Theory: ABCX

- **A** = Precipitating Event/Stressor
  - *The hospitalization of the family member*
- **B** = Family Crisis-Meeting Resources
  - *Family adaptability and integration*
- **C** = How the family defines the event
  - *How does the family interpret the event?*
- **X** = The actual crisis
  - *Changes in family roles*

Hill, 1958
The Double ABCX Model

McCubbin & Patterson, 1983
Vertical and Horizontal Stressors

• Vertical Stressors: inherited family “baggage” in the family’s developmental cycle (family pattern, myths and emotional issues)
  – Affects family level of functioning
* Serious illness = reactivation of “baggage” = anger & conflict

• Horizontal Stressors: part of the life cycle (marriage and children) and external stressors (war, death and chronic illness)
* Can affect nuclear and extended family- positively or negatively

Leon & Knapp, 2008
Family Boundaries

• *Outer boundaries*
  – structure must be protected but still allow for help from outside resources

• *Internal boundaries*
  – dictated by age and role

* Medical illness – can change role assignments

Leon & Knapp, 2008
Family Needs in the ICU

- Critical Care Family Needs Inventory (CCFNI)
- Predictable set of needs
  - Receiving assurance
  - Remaining near the patient
  - Receiving information
  - Being comfortable
  - Having support available

Other needs...

• Need to protect the patient (and other family members)
• Provide reassurance and support to the patient

Burr, 1998; Leske, McAndrew & Brasel (in press)
Family Adaptation

- Family Stress
  - Prior stressors
  - Patient injury
- Family strengths
  - Hardiness
  - Coping
  - Resources
- Family outcomes
  - Family well-being
  - Family adaptation

Leske, 2003
Research Challenges

1. Using/developing theory to guide the research
2. Choosing the appropriate family unit for analysis
3. Designing and testing interventions in collaboration with other disciplines
4. Developing and testing nursing interventions

Leske, 1991
Effects of Family Presence during Resuscitation after Trauma

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Research Design

• Multivariate, comparison

• Qualifications
  – Individuals, 18 years of age and older, admitted to FMLH SICU, meeting the standard definition of resuscitation

• Setting: Froedtert Hospital
  – 461-bed, non-profit, tertiary care hospital
  – Eastern Wisconsin’s only level 1 trauma center and academic medical center

• Study participants
  – Family members of critically ill patients with trauma from MVC and GSW and survive resuscitation
  – Need to be recruited within 24 to 72 hours of family member admission
Problem

• The family unit has been effected negatively by the lack of involvement in critical care
  – High anxiety and stress

• The need for information for the family is most prevalent in the initial critical care period. However, it is the need that is most often left unmet by health professionals
  – Leads to the family being dissatisfied with the patient care provided
Interventions

• Decrease family anxiety

• Increase family satisfaction

• Help family members perceive some control over the situation and plan realistic coping strategies

• Increase family understanding of the patient’s condition
Family Presence During Resuscitation

The FPDR option is a multidisciplinary intervention that is intended to:

- provide information,
- promote more realistic understanding of critical injury, and
- allow the family to be near the patient
Purpose

• To introduce Family Presence During Resuscitation (FPDR)
  – Innovative, multidisciplinary intervention
  – Intended to introduce family-centered care early in the critical care experience

• To bring understanding to an often neglected and vulnerable adult population who participate in FPDR option by describing if the experience fosters any initial positive family outcomes
Primary Aim

• To examine the effects of the FPDR option on family outcomes of anxiety, stress, well-being, and satisfaction

• To compare those outcomes in families who participate in FPDR to those families who do not participate in FPDR

• To reduce anxiety and stress among family members
Secondary Aim

- Examine any moderating effects of family strengths on family outcomes of anxiety, stress, well-being, and satisfaction
  - Strengths may include resources, coping, and/or communication
Conceptual Framework

Family Presence During Resuscitation After Trauma (FPDR)

Family Strengths
Resources
Coping
Communication

Family Outcomes
State Anxiety
State Stress
Well-being
Satisfaction

Family Presence

- Everything possible was being done for pt.
- Feeling of being supportive and helpful to pt & staff
- Maintaining family-pt relationships
- Closure on a life shared together
- Foster grieving

No Family Presence

- Concern that the event may be too traumatic for family
- Clinical care might be impeded
- Family members may become too emotional or out of control
- Staff may experience increased stress
- Staff are focused on the pt & may not be available to assist the family
- Nursing shortages
- Risk of malpractice suits
Goals

• To reduce anxiety and stress among family members
• To encourage health care team members to advocate for FPDR
• To improve the critical care experience for the family positively
Data Collection Tools

**Family Outcomes**
- S-STAI: State anxiety (self-evaluation questionnaire)
- ASD: State stress (acute stress disorder scale)
- FSI: State stress (family stressors index)
- FWBI: Well-being (family member well-being)
- FS-ICU: Satisfaction (family satisfaction with care in ICU)

**Family Strengths**
- FIRM: resources (family inventory of resources for management)
- F-COPES: coping (family crisis oriented personal scales)
- FPSC: communication (family problem solving communications)
Participation Rate

• FPDR group = 100%
  – Present
    • $n = 57$
    • Female = 42 (74%)
    • Male = 15 (26%)
    • MVC = 43 (76%)
    • GSW = 5 (9%)

• Control group = 85%
  – Not present
    • $n = 70$
    • Female = 59 (84%)
    • Male = 11 (25%)
    • MVC = 57 (82%)
    • GSW = 11 (16%)
Design Challenges

• Family presence depended on trauma team and availability of family member
Sample Challenges

• **Where are the family members?**
  
  – 25% Flight for life
  – 0 eligible/94 trauma calls (month 1)
  – 1/112 trauma calls (month 2)
  – 10/119 trauma calls (month 3)
  
  • 2 eligible to participate (2 were not)
  • 6 discharged from ED
Recruitment Challenges

- Underserved populations
- Nationally MVC and GSW has decreased
Inclusion/Exclusion Criteria

• One representative/family

• Expansion of exclusion criteria:
  – Potential organ donors
  – Police holds
  – Victims of domestic violence/sexual assault
Attention to Human Subjects

• Consenting process: Patient or LAR to sign a consent form and family member also needed to sign consent
  – Most patients could not provide informed consent
Procedure

- One member of research team approached family
- Presence group - interviewed first then completed tools
- Changes in data collection time - from 24-48 hours to up to 72 hours
  - Traumas occur at night - family members exhausted
  - Surgery may need to be performed
Other challenges

- The sensitive time we needed to approach a family-in the midst of a crisis
- Misunderstanding what researcher explained
- Learning who else to exclude (i.e. recent cancer diagnosis)
- Catching them at the “right” time
- “Come back later”
- Where to conduct interviews
Quiet Time for Nonverbal Patients in the MICU
Research Design

- A non-randomized, prospective, trial of a quiet time protocol on selected patient and nurse outcomes

- **Qualifications/Participants:** Patients admitted to the MICU, at least 18 years of age and nonverbal due to medical condition (intubated)

- **Setting:** Academic Medical Center, MICU
Problem

- Barriers to sleep in critical care are related to patient monitoring and treatment
  - Noise, lighting and medications contribute to lack of sleep
- No studies to date have examined the potential effects of quiet time on the use of sedation in critical care, or sleep associated with consecutive quiet time periods in the ICU.
- Primary aim: Examine the influence of a quiet time on the nonverbal patient population in a medical intensive care unit.
Research Questions

• Does sleep during periods of consecutive quiet time have an effect on patient measures such as heart rate, mean arterial blood pressure, respiratory rate, ventilator days, delirium and sedation scores?

• Does quiet time have an effect on delirium scores 24 hours before and after the intervention?

• What is the frequency of sedation doses over the subsequent 24 hours before and after a patient has received quiet time?

• How many interruptions occur during a quiet time? What kinds of interruptions occur during a quiet time?

• What is the nurse’s perception of the quality and quantity of patient sleep during the quiet time?

• What is the level of nursing satisfaction with quiet time?
Data Collection

- Patient demographic data: age, gender, and admitting medical diagnosis.

- Blood pressure, respiratory rate, heart rate, The Confusion Assessment Method for the ICU (CAM-ICU) scores (over a 24 hour period), Richmond Agitation and Sedation Scale (RASS) scores (before and after quiet time), time of last sedative and analgesic medications, as well as overall sedative and analgesic use within the last 24 hours.

- Date discharged from critical care, length of ICU stay and ventilator days

- Questions for the nurses include:
  - How would you rate the overall quality of your patient’s sleep?
  - How many interruptions did your patient experience during quiet time?
  - How long did your patient actually sleep uninterrupted during the quiet time period?
  - How quiet was the environment during the quiet time?
  - How satisfied were you with the quiet time?
Intervention/Procedure

- Get consent from LAR
- Quiet time: 2-4pm every day while enrolled in the study
- Lights go down in the unit
- For participants, lights off in the room, TV off, shades closed, and door closed
- Collect patient and nurse data
Theoretical Model based on Topf’s Environmental Stress Model (ESM)

Quiet Time Intervention

Environmental Variables
- Ambient Noise
- Patient Interruptions

Patient Variables
- Delirium
- Analgesics
- Sedatives

Sleep quality and quantity
Goals

• It is hoped that quiet time will:
  – Reduce the ambient noise and patient interruptions associated with nursing cares, tests and procedures, thereby increasing the quantity and improving the quality of uninterrupted sleep
  – Decrease the overall frequency of sedatives administered over the subsequent 24 hours after a patient has received a quiet time.
  – Consecutive quiet times will promote more RASS scores of zero and CAM-ICU negative scores after the intervention.
Challenges

- Catching the family member/slow accrual
- Patients meeting the criteria
- Not approaching at the right time
- “Come back later”
- “We have too much going on”
- Patient condition changes
- Concern that a quiet time was not the right intervention (want to sing and talk)
- Turned off by consent process
- Inability to protect quiet time
Why was participation so different in these studies?

• Quiet time for Nonverbal Patients in the MICU – 65% participation rate

• Dr. Leske’s FPDR study:
  – Control group – 85% participation
  – Intervention group = 100 % participation
Other comparisons?

- Family members in QT were approached in as few as 24 hours to up to 7 days after admission versus 24-72 hours in FPDR.
- QT study: All patients were unable to consent-relied completely on family member.
- Emergent care versus low risk study (shutting off the lights and closing the door).
- Did not need family input in the QT study—that was the purpose of FPDR.
What have your challenges been?
So what can we do about it?
Strategies

• Establish rapport
• Gain information about family assessment
• Provide for family comfort
• Convey acceptance and understanding
• Be flexible
• Know when NOT to approach or when to return
Strategies

• Learn from your mistakes
• Be patient and don’t appear to be in a rush
• Assure the family member close proximity to their loved one
• Try not to interfere with the family member’s access to information (i.e. don’t approach them during rounds in the unit)
Strategies

• Present options about how to complete the research procedure
• Clearly articulate the value of their participation
• Develop professional relationships with nursing staff-they know where the family goes and what happens in that family
• Be aware of interviewer effects-experience, training and supervision of data collectors = significant contribution to response rates and effects

Moriarty, 1990
Questions????
References


Leske, J.S., McAndrew, N.S., & Brasel, K.J. (in press). Experiences of families when present during resuscitation in the emergency department after trauma. *Journal of Trauma Nursing*. 


