

A Qualitative Study of Family Members of ICU Patients who Require Extensive Monitoring

Claudia DiSabatino Smith, PhD, RN, NE-BC
Kristi Custard, BSN, RN, CCRN

Baylor St. Luke's Medical Center
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Disclosure

Authors: Claudia DiSabatino Smith, PhD, RN, NE-BC

Kristi Custard, BSN, RN

Learner Objectives:

1. Describe the elements of the research study.
2. Discuss the findings of the research study.

The authors state that they have no conflict of interest.

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Background & Significance

1. Monitoring technology in last 10-15 yrs - high tech and complex
2. Computer age - more sensitive invasive and non-invasive monitors
3. Healthcare professionals use to monitor and deliver therapy
4. Growing gap between healthcare professionals and patients' family members



Background & Significance

- Situational anxiety arises from worry about:
 - Patient's suffering and impending death
 - The procedures
 - Possible complications
 - The equipment used in caring for patient ¹
- Family members experience distress when there is poor communication ^{2, 3} that results from the inability to:
 - understand information
 - recall information
 - receive information ⁴

Background & Significance

- >50% of ICU patients' family members are at moderate to high risk for developing psychological distress long after the discharge or death of the patient.⁵
- Psychological distress includes
 - Depression
 - Anxiety
 - Post Traumatic Stress Disorder (PTSD)
- Those that receive **incomplete information** are more likely to suffer from symptoms of PTSD.⁶
- Implementing proactive approaches to communication with family members decreases the occurrence of anxiety, depressive symptoms, and PTSD.³

Purpose

Background and Significance

The purpose of this study was to:

Explore the experience of family members of post-cardiac surgery ICU patients with whom extensive monitoring technology was used, as it relates to education provided to family members.



Definition

High tech, extensive monitoring is defined as:

1. Continuous monitoring that goes beyond the standard ICU monitoring that consists of heart rate and rhythm, oxygen saturation, invasive and non-invasive blood pressure, and mechanical ventilator.
2. High tech, extensive monitoring includes the use of specialized equipment that not only monitors the patient, but may also provide therapy to a subset of very complex patients.
3. Extensive monitoring includes hemodynamic monitoring, central venous pressure monitoring, and/or the use of one or more of the following: left ventricular assist devices (LVAD), hemodialysis (HD), continuous veno-venous hemodialysis (CVVHD), continuous renal replacement therapy (CRRT), and intra-aortic balloon pumps (IABP).

Theoretical Framework

The Roy Adaptation Model, Sister Calista Roy (1999)

- Critical Illness causes a disruption in life.
- It requires a period of adjustment (compensatory process)
- Adaptation is iterative; occurs after a period of adjustment
- Events in adjustment period determine outcome of adaptation
 - Positive
 - Negative
 - Complete
 - Incomplete ⁷



Sister Calista Roy

Study Design

- Approval
 - Nursing Research Council
 - Hospital IRB
- Informed Consent
- Mixed Methods
- Purposive Sampling
- Inclusion Criteria
 - English-speaking family members of patients who had cardiac surgery and required extensive monitoring equipment
 - Family members who visited in ICU while extensive monitoring in place
- Digital recordings transcribed by professional transcriptionist
- Transcriptions verified by Principal Investigator



Data Collection Methodology

- Researcher-generated demographic data form
- Use of a semi-structured interview guide for family interviews
 - *“Describe for me what you saw when you entered the room to see the patient after surgery?”*
 - *“Tell me about what you were thinking when you saw the patient connected to the monitors/machines.”*
 - *“What did the nurses or doctors tell/teach you about each of the monitors/machines?”*
- Spielberger’s State Trait Anxiety Inventory (STAI)
- Interviewed families as a whole (≤ 4 family members), not each member individually
- Interviews conducted in private hospital office



Data Analysis and Management (Qualitative)

- Transcription
- Verification of transcription by Principal Investigator
- Diekelmann's descriptive phenomenological analysis method
 - 7-Phase Process
 - Read all transcripts for overall understanding of phenomenon
 - Write interpretive summaries of each interview
 - Analyze select text
 - Identify common meanings
 - Resolve disagreements on interpretation
 - Relationships among themes emerge
 - Themes with exemplars ⁸
- Review of transcripts and interpretive findings for accuracy and consistency by qualitative research colleague



Data Analysis and Management

- Analyze anxiety level of each participating family member
- Determine composite anxiety score of each family unit
- Calculate frequency tables of demographic data and STAI scores
- Compare composite scores to qualitative findings to explore any existing relationships
- Iterative analysis, coded transcripts
- Thematic analysis



Quantitative Findings

Demographics

- 71% female
- 86.7% Caucasian
- 57% Spouses of patient
- Age range 29 – 77 years
- Average age 57.4 years
- 71% patients had standard + 4 additional monitors / machines
- 29% patients had standard + 3 additional monitors / machines

Anxiety Level

- STAI Level – 4 families low to medium anxiety level
- STAI Level – 1 family high anxiety

Anxiety levels in 80% of family members were in the bottom 50th percentile.

20% of family members had anxiety levels above the 70th percentile

Qualitative Findings

Emerging Themes

1. *Overwhelmed by all of the machines*
2. *Feelings of uncertainty*
3. *Methods of coping*
4. *Meaning of the numbers on the machines*
5. *Need for education*
6. *Nurses are wonderful*

Qualitative Findings

Overwhelmed by all of the machines

- When we came into the room we saw, “all the monitors, you see the nurse’s computer and then all of the monitors and all the wires, the tubing, the nurse....”
- “... a lot of bags of liquids, a lot of tubes... and really the size of the machines, like the bulk of it looked like he had 2 huge computer stations on both side[s] of him, tied into him. ...”
- “Even though everybody told me what to expect and stuff, it was still worse than I thought it would be. Even in my worst imagination, it still was worse.”

Qualitative Findings

Feelings of uncertainty

- “I was wondering if the machines were doing all of the work for him, if he was doing any of the work for himself or if he was going to need that type of equipment for the rest of his life. I wondered, “if that was something that he would recover from. It didn’t seem...it just looked like...how could he possibly recover from all of this?”
- “My worry was how long was he gonna be sedated. I know they were sedating on purpose, but was he gonna come out of the sedation?”

Qualitative Findings

Methods of coping

- “I tend to focus on the blood pressure, the things that I’m familiar with. I don’t really look around a lot. He was probably there a week before I noticed there was a sink in the room [where] I could wash my hands.”
- “I just like asking each [staff member] person if they would tell me this again... I just like to look and point and say, ‘what’s that, and what’s that?’”
- “I looked at [patient name] lying there, and I’m thinking, ‘I’m so happy and he’s happy and I know he’s in a lot of pain, but I just think how blessed we are that he got all of this and [they’re] taking care of him. They didn’t have all of this, years ago.’” “The other people were so generous to us. The other family so willingly gave everything that child had...”

Qualitative Findings

Meaning of the numbers on the machines

- “We saw “graphs, a lot of numbers, a lot of information that would seem to mean something, but you don’t really understand what.”
- “How do you know what the norm is? Do you know that that’s a good number that you are looking at?”
- “Each patient would have different parameter, but even if we just knew what each color and line meant and what it was measuring, I think that would have been very helpful.” “...parameters of what you would expect for the heart beat, what good blood pressure numbers are, and maybe your oxygen saturation.”
- “...I didn’t know what any of those numbers and things meant on that monitor that heart beating and blood pressure and I don’t remember what any of the rest of them were....”

Qualitative Findings

Need for education

- “I think the more education ... [on] the technology the better. That was the first thing I did... I’ve never heard of an LVAD before this and I went straight home and just spent hours just researching it and reading about other patients’ experiences and the process of LVAD recovery. To maybe have that as reading material in the waiting room, or maybe have an iPad app that gives you... meet the hospital equipment.”
- More education “gives you something to feel empowered, to feel like you have a little more control of the situation. But besides that, it would be helpful for family members who want to understand more about what is going on.”
- “We were given a brochure on the LVAD device...” I do believe that it’s your personal responsibility to become educated in something that truly is a life-changing event.... I’ll never be an expert, but I’ll be knowledgeable and with knowledge comes power.”

Qualitative Findings

Nurses are Wonderful

- “Nurses did a wonderful job” and “taught them all that they needed to know”.
- As the interview progressed families consistently admitted, “there were things that it would have been helpful to know.”
- “Nurses [are] phenomenal. Very personable and upbeat. Without those people it would seem very cold.”
- “They’ll explain anything you ask.”
- “Nurse gave me a hug [when I asked about numbers on screen] and said, ‘You let us worry about the numbers. You just take care of him and give him love.’”

Implications

Clinical

1. Hospitals need to develop printed teaching materials for lay visitors that includes the use of modern equipment, and basic ICU care.
2. Caregivers need to provide family members with both **written** materials and **verbal** explanations about the equipment in use, ICU routines, normal parameters of vital signs for this patient, and other information that may help to reduce visitors' anxiety.
3. Caregivers should not assume that visitors comprehend all that has been told to them by the physicians or other hospital staff.

Implications

Research

1. Replicate study using a culturally diverse sample to determine if findings are generalizable across cultures.
2. Replicate study after developing and implementing the use of written education materials specific to high tech monitoring equipment and ICU nursing practices to determine effectiveness of such materials.
3. Replicate study after developing and implementing the use of electronic interactive education materials specific to high tech monitoring equipment and ICU nursing practices to determine effectiveness of such materials.

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Dr. Claudia DiSabatino Smith csmith1@stlukeshealth.org
Director, Nursing Research
CHI St. Luke's Health – Baylor St. Luke's Medical Center
Houston, Texas U.S.A.