A RESEARCH STUDY TO UNDERSTAND PATIENT AND FAMILY EXPERIENCES WHEN MOVING FROM THE ICU TO A HOSPITAL WARD

The ICU To Hospital Ward Experience ... summary of Findings within Major Categories, and Recommendations

Adapted from: Boulton D, Oswell D, Oxland P. Patient and family experiences when moving from the intensive care unit (ICU) to a hospital ward. Patient & Community Engagement Research (PaCER) Report 2015.

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Intensive Care Unit (ICU)

One-on-one, specialized care utilizing life support technology and significant resources

ICU to Ward Transition

• Risky medical transition
• Very challenging for patients and families

Hospital Ward

Fewer resources and reduced nurse to patient ratio
What Families Do

- Reduce vulnerability
- Provide care
- Interact with providers
- Keep the story
- Advocate
- Figure it out
What Families Do

Reduce vulnerability

Families provided social interaction and support for the patients, and oriented delusional patients.
What Families Do

Families wanted to help with care, but didn’t always know how or what to do, and struggled with understanding their role on the team.
What Families Do

- Reduce vulnerability
- Provide care
- Advocate

When families felt their concerns were not being adequately addressed, they advocated for the vulnerable patient regarding the plan of care.
Because families observed the patient closely, they came to know the patient best, and often identified serious medical concerns and possible solutions.
What Families Do

Families pieced together the entire health journey from ICU to home as best they could, using a variety of methods to keep track of the journey.

- Reduce vulnerability
- Provide care
- Advocate
- Keep the story
- Figure it out
What Families Do

Reduce vulnerability

Provide care

Interact with providers

Patients and families wanted to engage with providers in informative and caring two-way conversations.

Keep the story

Advocate

Figure it out
What Families Do

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Model for Engaging Families and Patients

Enhanced interactions with providers

- Reduce vulnerability
- Feel treated as a person
- Create continuity
- Keep the story

Positive Outcomes

- Provide care
- Be engaged with the team
- Feel confident and safe
- Advocate
- Figure it out

What Families Do
When patients and families interacted with providers who were caring and compassionate, they felt the patient was being treated as a person, not just a patient, which helped reduce their vulnerability.

“There was one nurse that was really good, shone above the rest. She was compassionate.”

“It made him feel more welcomed and more relaxed when he was able to chat with the nurses and the people making rounds.”
When families received information from providers regarding patient care, they were able to participate in the patient’s care and became engaged with the healthcare team, resulting in better care.

“They kind of made us part of it, which was really nice. We sat down, and it was J, his doctor, all his therapists, and my parents, his dad, and they involved us in what the plan was.”
Model for Engaging Families and Patients

When providers listened and acted on concerns voiced by families and patients, families were more confident the patient was receiving appropriate and safe medical care.

“Advocating is exactly what I had to over and over and over. The positive part is I ultimately got a weekly meeting with the care team, therapist, and charge nurse.”

Positive Outcomes

What Families Do

- Feel treated as a person
- Be engaged with the team
- Feel confident and safe
- Advocate
- Figure it out

Enhanced interactions with providers

Caring
Informative
Two-Way
When families participated in two-way conversations with providers who listened to the patient’s ‘story’, the exchange of information contributed to continuity in the patient’s care.

“I have a list of all her allergies. I have a list of hospital stays ... I have a list of procedures, where they were done ... And they [providers] are like, oh my God, this is helpful. They appreciate the information.”
Model for Engaging Families and Patients

Enhanced interactions with providers

- Reduce vulnerability
- Providing care
- Be engaged with the team

What Families Do

- Feel treated as a person
- Be engaged with the team
- Feel confident and safe

Positive Outcomes

- Advocate
- Figure it out
- Create continuity
- Keep the story
The Hospital Transfer Experience

Before Transfer In ICU
- Experiencing the ICU
- Emotional response to being told about move

Transfer to Ward
- Being informed about timing of move
- Concerns about transfer
- Transfer of information

After Transfer On the Ward
- Feeling disoriented
- Feeling vulnerable
- Adjusting to ward
Patients and families perceived ICU as a highly technical and safe environment with one-on-one care provided by compassionate staff who were skilled communicators.

“It was a really wonderful combination of professionalism and concern. They’re always approachable. They’re always there. The communication skills of the folks in the ICU are stellar.”
The Hospital Transfer Experience

When told about the move, patients and families experienced a range of feelings, and their emotions were often mixed.

“We were thrilled. On one half, we were nervous, but on the other half, we were thrilled.”
The Hospital Transfer Experience

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Families wanted to know when the patient would be moved, because they wanted to accompany the patient during the move.

“I go on a break, and just came back to find a vacant spot. It was totally frustrating. Where did my wife go? Did she die or did she ...?”
The Hospital Transfer Experience

Before Transfer
In ICU
- Experiencing the ICU
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Transfer to Ward
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Patients and families were concerned the ward would not meet the patient’s needs and with the reduced level of care on the ward.

“One day you’re meeting the protocols to be in the ICU, because you’re that sick, and the next day you’re not. It’s such a drastic transition ... You’re really going from the moon to earth, and there’s so much room in-between.”
The Hospital Transfer Experience

Patients and families assumed the medical information was transferred to the ward, but in hindsight, questioned this assumption.

“I’m sure it [medical information] got there. But the person now responsible, did they actually get it, go through it, understand it? There’s so much that they have to go through and it takes time.”
The Hospital Transfer Experience

Patients and families did not know the physical layout, staff, ‘rules’ or schedule on the ward and did not receive an orientation.

“But it’s not familiar anymore. You’re not exactly sure what the rules are, what they aren’t. It looks less spiffy, less high tech. It feels awful. You realize that until everybody gets their bearings, you, the patient, and the staff around you, it’s a bit of a black hole. You’re in a bit of a vacuum.”
After Transfer On the Ward

Before Transfer In ICU
• Experiencing the ICU
• Emotional response to being told about move

Transfer to Ward
• Being informed about timing of move
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After Transfer On the Ward
• Feeling disoriented
• Feeling vulnerable
• Adjusting to ward

Patients felt vulnerable on the ward because they were alone and confused. Families felt isolated and unsupported on the ward compared to the ICU.

“And I was alone because it was my first day, my first night in a strange place, and I had nobody there that I knew.”
The Hospital Transfer Experience

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“10 different nurses, 10 different personalities, 10 different ways of doing things, 10 different priorities.”

“We actually never did know who [physician] was looking after Dad on the Neuro Unit.”

Patients and families faced challenges adjusting to the ward, reduced level of care, discontinuous and variability in care, and access to physicians.
Creating Continuity in Health Journey

The Hospital Transfer Experience

Before ICU

Before Transfer In ICU
- Experiencing the ICU
- Emotional response to being told about move
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Transfer to Ward

After Transfer on the Ward

Transfer Home

‘New Normal’

Medical care takes place in separate specialized units

Families create continuity between units by Keeping the Story
Recommendations for Improvement
(Transitions of care from ICU to the ward)

1. Keep patients & family members informed about the move
2. Provide orientation to the ward
3. Facilitate families’ attempt to keep the patients’ story
4. Improve provider to patient & family communications
5. Provide dedicated navigator/advocate
6. Engage families with care team
1. Keep patients & family members informed about the move

- Explain ICU discharge criteria
- Have earlier discussion & preparation relating to transfer
- Inform when patient being transferred (phone call, pager)
- Give family opportunity to accompany patient during transfer
2. Provide orientation to the ward

• Inform families that patients may need more support on the ward than in ICU

• Offer families an orientation to the step-down unit or ward before transfer

• Provide orientation for patients & families when arrive on ward (ward physical layout, ‘rules’, schedule & staff; attending physician schedule)
3. Facilitate families’ attempt to keep the patients’ story

- Encourage families to keep a journal
- Encourage staff to contribute to journal (including layman’s version of medical chart)
- Give patients and family members ability to access medical records electronically
4. Improve provider to patient & family communications

- Prepare summary to convey critical patient discharge information & concerns (for ward, patient & family)
- Share patient’s plan of care consistently & honestly
- Include patients with their plan of care
- Listen to family members’ concerns as they know patient best
- Ensure questions are answered
- Ensure language translation services are available as needed
5. Provide dedicated navigator/advocate

- Provide a dedicated healthcare professional to support patients & family members throughout their health journey - with a patient-focus, not a unit-focus
6. Engage families with care team

• Discuss with family members their role in patient care

• Avoid relying on family members to provide personal care for patients (toileting, feeding, exercising, housekeeping duties)
The overarching message was the need to shift towards meaningful engagement of families with the healthcare team, by *valuing the benefits of family expertise* and *giving them a role*.

“What is normal for health care providers is not normal for patients and families.”