

# THE TRAUMA OF THE TRANSITION: PARENT EXPERIENCES OF TRANSITION FROM PEDIATRIC INTENSIVE TO ACUTE CARE

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## PROBLEM, PURPOSE, RESEARCH QUESTIONS

A visit to the pediatric intensive care unit (PICU) is associated with negative developmental and psychosocial outcomes for pediatric patients and their families that can persist for months or years. The framework of PICs-p has been introduced to acknowledge these effects and spur intervention development; however, little attention has been paid to how specific events in the child's healthcare trajectory may relate to parent/caregiver psychosocial outcomes. Therefore, the purpose of this study was to explore parent/caregiver perceptions of transition from the PICU to acute care and identify opportunities for intervention and support during this medically and psychologically vulnerable time. The research questions included: 1) How do parent/caregivers of pediatric patients describe their child's care in the PICU, acute care unit, and the transition between the two; and 2) what stressors and support do they identify when transitioning between the units?

## METHODS

### Research Site:

- Monroe Carell Jr. Children's Hospital at Vanderbilt
- Level 1 trauma center with a tertiary PICU (42 beds) and dedicated CVICU (18 beds)

### Study Design:

- Retrospective Mixed Methods Investigation
- Quantitative Perception Survey with Optional Follow-up Interview

### Participants:

- The study consisted of 55 parent/caregivers, 18 of which completed an additional interview

Intensive Care Unit Type			
	Pediatric Cardiac ICU	26	47.3
	Pediatric ICU	29	52.7
Child Age	Less than 12 months	26	47.3
	1 to 2 years	4	7.3
	3 to 5 years	8	14.5
	6 to 12 years	7	12.7
	Over 13 years	10	18.2
Days Spent in ICU	Less than 24 hours	2	3.7
	1 to 2 days	4	7.4
	3 to 5 days	13	24.1
	5 to 10 days	11	20.4
	More than 10 days	24	44.4
Days Spent in Acute Care Unit	Less than 24 hours	5	9.6
	1 to 2 days	9	17.3
	3 to 5 days	11	21.2
	5 to 10 days	9	17.3
	More than 10 days	18	34.6
Reason For Child's Admission	Cardiac, Respiratory, or Gastrointestinal Surgery	17	30.9
	Heart Condition/Defect	11	20.0
	Brain Disturbance/Injury	6	10.9
	Organ Transplant	3	5.5
	Infection/Virus	7	12.7
	Autoimmune Disease	2	3.6
	Accident	3	5.5
	Other	4	7.3

Themes	Quotations
Poor communication between providers and caregivers	<p><b>Caregivers described abrupt transition</b>                      "It was pretty much out of the blue. We are going to move her down." (40)                      "They were like, "Oh, well you've been off [the vent], so you know you're getting like kicked upstairs, right?" And I was like, "What?" (9)</p> <p><b>Caregivers frustrated over lack of communication between providers</b>                      "But there were times where one team may say, "Okay, we're going to do this, because of this" and the other team would say, "Well, we're going to do this", and the plan would be different, and the communication was a little bit lacking between the two."(33)                      "I can remember having to re-explain the entire story like what happened that night, what it led to. I kind of had to spell it out for them... they should have known already. They shouldn't have had to ask." (17)</p>
Parents wished for more preparation prior to transition	<p><b>Caregivers wish they were given more information about the transition and the acute care unit to decrease stress</b>                      "not really knowing what was going on in that floor after coming from the ICU floor."(60)                      "if maybe somebody from step-down came over and introduced themselves, and... told me on the front end, like, "Hey, standard of, the level of care is the same, but we recognize that we're gonna be all new faces, and our processes and procedures are a little different, 'cause we're preparing you to go home... maybe it would have at least like set, set an expectation of how things were, what the next step looked like." (16)</p>
Difficult to leave PICU care providers during transition.	<p><b>Caregivers are afraid to leave PICU because of comfort and confidence they had in PICU medical providers.</b>                      "And I actually said to one of the, doctors, in the PCICU, I said, "Can we stay here as long as possible? Haha. And just have a short time on the step-down floor? Because I know all of you guys, and you all know me, and you all know Juliette." (6)                      "And, and I think there's like an emotional component to it a little bit. And part of that is just, like, we've gotten to know the team here. Like, we know the names, the faces are familiar, there's a trust that's been established. And then it's like, "Okay! We'll see y'all later!" .. and although it's like exciting, 'cause you're like, "Yes, I'm one step closer to home", um, it's also terrifying." (16)</p>
Importance of advocating for children throughout care trajectory	<p><b>Caregivers discussed the importance of learning to ask questions and speak up to providers</b>                      "You are there to advocate for your kid and they are there to advocate for your kid as well but sometimes you know your kid best so sometimes you need to ask question and sometimes like I said if you feel weird you just kind of need to kind of take that step and ask." (56)                      "I felt like we really had to advocate a lot more in that step-down room, you know, there was a lot more call button being pushed." (17)                      "I would just recommend that they ask questions and don't be afraid to ask even the dumb questions you know before stepping down because that's probably the best time to get your questions answered." (60)</p> <p><b>Some caregivers felt that they needed outside support to advocate for their child</b>                      "But then when we got to the floor it was kind of like, we were at the mercy of whoever was coming in, whatever you know we didn't have somebody that was kind of like an advocate."(31)                      "And so, I think if somebody would have come in and said, "Hey guys! What's happened so far today?" and just kind of giving you the opportunity to process that, I think would have been so helpful." (10)</p>

## RESULTS - QUANTITATIVE

1. Participants rated the quality of intensive care higher than the quality of acute care ( $p < 0.001$ ,  $d = 6.02$ ).
2. Participants rated their satisfaction with the transition as lower than their satisfaction with their intensive care and acute care stays ( $p < 0.05$ ).

## RESULTS QUALITATIVE – "CHAOS"

Poor communication between providers and between providers and caregivers

- Parents were shocked by the quick transition and felt that during the transition new providers did not know important information regarding their child's health needs.

Parents wished for more preparation prior to transition

- Parents wish they were more aware of the medical milestones needed to transition, the differences in the acute care floor functioning, and the resources that were available to them.

Difficult to leave PICU care providers during transition

- Pediatric patient caregivers developed close relationships with PICU providers which made leaving these providers during the transition scary and emotional.

Importance of advocating for child, especially in the acute care unit

- Parents expressed that they had to learn to be comfortable speaking up and asking questions about their child's health. This was particularly mentioned as being necessary in the acute care floor where patients receive less attention from providers and there are fewer parent to caregiver interactions.

## CLINICAL IMPLICATIONS

- A standardized transition preparation process is needed for pediatric patients and their caregivers. This process should include a transition coordinator, an ICU transition checklist, and a transition evaluation instrument to ensure patients and their family's needs are met.
- Improved communication and documentation procedures are needed in the transition. This could be implemented through transition huddles between the medical and psychosocial supports to increase across unit communication.
- Family engagement and education support are needed throughout the care trajectory. This could include ICU diaries and informational access.