Partnering with Parents and Families to Provide Safer Care: Seeing and Achieving Safer Care through the Lens of Patients and Families

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Opinion statement

Humans function best within relationships that are supportive, nurturing, collaborative, and filled with mutual respect. Why, then, do these relationships seem to disappear at the clinical bedside? For both clinicians and patients and their families, the need for empathy and compassion is never greater than during a time of sickness and tragedy. This is especially true in pediatric care, among some of our most vulnerable patients. The best medical care and the safest outcomes derive from collaborative relationships. In true partnerships, clinicians feel comfortable expressing their own humanity, and patients and their families are satisfied that they are being heard. With empathetic communication to family-centered care process, we can create a profound setting for healing.

Introduction

The principles of family-centered care are applicable in all clinical settings. In critical care areas such as PICU, these are an essential requirement for holistic care. These principles should be grounded in collaborative

relationships between healthcare professionals and parents. Key requirements for the establishment of these collaborative relationships include empathy and compassion. Without empathy, “patients are dehumanized and the physicians’ focus shifts from

the whole person to target organs and test results” [1]. The deficit of compassion within the healthcare system is linked to adverse impacts to patient and family satisfaction, patient safety, and the well-being of the clinician [2].

Collaboration and empathy—using the lens of quality improvement

The aim of healthcare institutions is to promote healing and decrease suffering. But these same institutions are not consistently developing systems and processes that foster the collaborative relationships so critical for optimal outcomes. “We are not positioning clinicians, i.e., physicians and nurses, to empathize and to share kindness (compassion),” [3]. By continuing this practice, we are not enabling clinicians to partner with parents and families in a collaborative relationship. Thus, we are adversely impacting care and patient safety in the PICU.

Conneman shares a story of a child dying in the PICU during a particular shift. As the residents come together to debrief, each makes note of diagnoses, treatments, treatment plans—but not one mentioned the death of the child. Not one considered the impact this child’s death had on them, i.e., the impact of losing a child or the frustration they felt as doctors who were unable to save the child.

The residents were trained to be stoic, to follow the data, the facts, to become machine-like. They suppressed their vulnerability, their humanity, and yet what they needed and what the child’s parents and family needed were those very things—their humanity, their empathy, their kindness, their compassion. Conneman found these residents “were ashamed to show their humanity.”

Riess blames our medical education system for some of the decrease in empathy between a clinician and patient and family, claiming that much of this separation is due to the medical education system’s emphasis on emotional detachment, clinical neutrality, and over-reliance on technology that limits human interactions [1]. These may become their own defense mechanisms.

Without shared empathy and compassion, there will not be true partnership between clinician and patient, parent, and family. Limited shared decision-making and collaboration will lead to adverse impacts on quality and safety. As Table 1 indicates, several steps may be taken to improve the level of collaboration among patients, families, and clinicians.

In a recent CAPHC webinar series, Dr. Trey Coffey expresses her experiences with several unique partnerships in care that truly make care for children safer, “We do get further faster doing this work together” [4].

A director of case management at a small community hospital recently shared a story of how leadership failed to support front-line staff:

“You don’t know how it is to call a code, take care of the patient and support the family. You don’t know how it is when someone dies on your watch and no one is there afterwards to support the care team. You talk about initiatives and not about the people.”

Table 1. Key lessons to have parents and families as partners to develop compassionate care

- ? Psychosocial support for clinical teams and families
- ? Schwartz Centre Rounds to self-reflect and learn
- ? Inclusive family-centered rounding
- ? Parent rounding to involve all
- ? Ongoing risk assessment and sharing
- ? Ensure that parents remain with children at key intervals, e.g., pre- and post surgery
- ? Treat the child as a person not a patient
- ? Focus on the special needs of adolescents
- ? Ensure comprehensive bereavement support

Clearly, this team was not well positioned to partner with their patients, parents, and families. And just as clearly, the system was placing patients in harm's way as this care team was burning out.

Burn-out is a significant concern in the medical industry. Emotional support can help reduce stress levels. "Beyond all of the wonderful treatments modern medicine has to offer, the most profound healing comes from a bond of shared humanity. To pretend otherwise is to deny our humanity" [5].

Case study—developing empathy and compassion by caring for the carer

The Cincinnati Children's Hospital Medical Center PICU team has implemented a number of initiatives to instill empathy and compassion in their care team and ensure clinician resiliency. The expectation is that resilient clinicians will be better positioned to be empathic and compassionate and will have greater ability to establish collaborative relationships and partnerships with parents and families and thus improve care and safety (Cincinnati Children's Hospital Pediatric Intensive Care Unit care team (March 24, 2015). Patient and Family Experience in the PICU—telephone interview).

The hospital used the lens of quality improvement to create an implementation process which focused initially on one patient 1 day, and the next on high-acuity patients (i.e., small tests of change). Once the right questions and processes were tested through the plan, do, study, act cycle, the team was able to expand to scale.

Through their participation in a research study which focused on staff resilience, the hospital also identified two of the most meaningful requirements to maintaining staff resiliency in their institution:

- (1) A psychosocial team devoted to the PICU and
- (2) The implementation of Schwartz Center Rounds® [6]

The psychosocial team and the candy dish

The psychosocial team (social work and pastoral care) devoted to the PICU has a candy dish inside their office. "The 'candy dish' is very simple, well loved, and provides a conduit for informal debriefing, compassion and support for staff,"

according to Paul C. Beckman, BCC, Staff Chaplain I, Emergency/Trauma/PICU (Cincinnati Children's Hospital Pediatric Intensive Care Unit care team. (March 24, 2015). Patient and Family Experience in the PICU—telephone interview). The team ensures a bowl full of candy is available to the psychosocial staff. When they are feeling low (literally or figuratively), they come together informally to debrief and share experiences. They are allowed to discuss their challenges of the moment, the day, the week to explain how the illness or passing of a child has impacted on them. It is a safe place to think things through out loud, feel both empathy and compassion, and to experience humanity and compassion for themselves. This then extends to their patient-facing moments so they are positioned to collaborate and partner with patients, parents, and families and ensure optimal safety and outcomes.

Schwartz center rounds

These rounds give "healthcare providers a regularly scheduled time during their fast-paced work lives to openly and honestly discuss the social and emotional issues they face in caring for patients and families. In contrast to traditional medical rounds, the focus is on the human dimension of medicine. The premise is that caregivers are better able to make personal connections with patients [and parents and families] and colleagues when they have greater insight into their own responses and feelings." (Cincinnati Children's Hospital Pediatric Intensive Care Unit care team. (March 24, 2015). Patient and Family Experience in the PICU—telephone interview)

Collaborative Relationships and Partnerships

These and other measures have led the care team at Cincinnati Children's Hospital Medical Center to develop collaborative relationships and partnerships with parents and families within the hospital. This has led to a number of innovations that have shown promise with early positive impact within the PICU:

- Implementation of "Parent Rounds/Family Centered Rounds." Staff engages family in "rounding" of their own child within the PICU. A cross-functional team participates, including doctors from different disciplines, nursing team, parents and families, social workers, and care managers. The focus is to review, discuss, and modify the care plan collaboratively and as partners. This process engages the parents and families and helps clinicians gain insight and wisdom, which ensures open communication and questions from multiple perspectives being answered. The focus is on the patient, parent, and family perspectives and wishes, rather than the convenience of the clinical staff. "This has led to a change in culture; a focus on the patient risk rather than just on the number of lines and process measures."

The Cincinnati Children's Hospital PICU care team's efforts signify that moving to family-centered rounding requires significant training and a paradigm culture shift. To recognize the amount of engagement the family desires, and the level of communication required while eliminating jargon for optimal understanding, represents a significant step forward. This demonstrates the collaborative (empathic/compassionate) relationship that all care facilities can establish.

- “Ongoing Child Risk dialogue.” By engaging with parents and families in an ongoing dialogue, parents are encouraged to share (and clinicians are trained to accept) information based on the parent’s recognition of their child’s temperament, pain tolerance, skin color, and mood changes as they compare to baseline. Parents understand their children best, and this wisdom can be leveraged for the optimal care and safety of their child.
- “Post-Surgical Parent and Family Presence.” Early data shows that children whose parents were present and who assisted with pain assessment and management post surgery cried less, were less restless, and required less medication.
- “Seeing through the eye of the patient, parent and family during the design/thinking process.” The hospital installed information “white boards” on the bathroom door in each room to view the child as a whole person rather than strictly as a diagnosis. “Once we see through their eyes then we have data to apply to change the system.” Pictures of the child engaged in their favorite activity bring a new dimension to the care team and thus provides additional data points for engagement and co-created care planning.
- “Parent Guide book.” Using the lens of the parent and family, the Parent Guide book is redesigned biannually with their input to empathize and engage new parents and families in the care and safety of their children. Recent improvements include a letter from other parents who have shared similar experiences and an acknowledgment of how scary things may appear. These improvements are positioning parents and families to feel less alone and more part of a community.
- “Parent and Family Advisory Councils.” The Parent and Family Advisory Council meets monthly to assess initiatives for implementation, effectiveness, and modification (continuing the lens of quality improvement to improve care).

With the perspective of “we are the experts in healthcare and you are the expert in the care of your child” over the course of a year, Cincinnati Children’s Hospital Medical Center has recorded a decrease of harm to PICU patients by two thirds (Cincinnati Children’s Hospital Pediatric Intensive Care Unit care team. (March 24, 2015). Patient and Family Experience in the PICU—telephone interview). They attribute their success significantly to the parent partnerships they have created.

What really matters—understanding the parent and family

With the experience of having interviewed multiple families over the years, we thought that the parent comments would resonate with many of those reading this paper. We were pleased to learn that the care of children in the past 5 years has improved tremendously from the parent’s perspective, although there is always room for improvement. Continual parental and child feedback will result in genuine partnerships that improve care. Below are stories from parents about their child’s hospital care.

- “Having a child with special needs, you sometimes become a frequent flyer to PICUs. They get to know you and your child. They also realize that the

parent knows the child best so they include you in your child's care. You sit in on Rounds and participate. They listen more now. They ask you questions if you think this or that will work better for your child. Most want your advice. Because of Aaron's condition, I've become a mentor to other new families in the PICU and try and help them feel empowered, educated, and try and lessen their fear. We've had a few problems where there's been a nurse who didn't care what the parent's concerns were but in general the clinicians become a part of our family." [7]

- We were terrified as we arrived at the PICU. We drove ourselves as our child was transported by ambulance from a neighboring Community Hospital, where something reportedly went terribly wrong during anesthesia, resulting in cardiac arrest and pulmonary hemorrhage. We were directed to the large, locked, steel door that boldly stated, RESTRICTED AREA. We froze not knowing how to get to our child. Why wouldn't the door be welcoming to families? He needed us. Looking back, I think that the door represented the walls of silence that we would soon encounter from the Community Hospital after his death.

Finally, the ambulance driver arrived soon after and graciously showed us how to enter with his door code also telling us that he was pleased to say that Justin had made it there alive, as if he was afraid that he wouldn't have survived the mile ride. How could this have happened during a simple procedure? Our lives had been changed in an instant. We had never felt so alone. Where was the empathy at the other hospital?

I fondly remember the kindness from one of the PICU doctors who has remained our friend. He cared, explained what he could about the events and empathized with our pain and sorrow. We were in shock so we didn't ask many questions at first but he would have listened as we have had many questions since about what could have gone wrong. We had no doubt that the PICU team tried everything to save him...but they couldn't.

Transparent, honest conversations are what families want and need during a PICU stay, or for that matter, any healthcare experience. They need to be totally involved in treatment plans, shared-decision making, Rounds, access to all records and any other meetings and discussions that involve their child. We expect your best and we expect to be a member of our child's care team, also. Even though we may not know medicine like the clinicians do, we do know our child." (Micalizzi).

- "I asked, begged, complained, for 20 h for somebody to tell me why my child (Leah) was in such pain, yet becoming so lethargic she wasn't able to hold her own head up. Her dad told the nurse before he left, "do not give my child any more narcotics until I can speak to a doctor" and of course, we were ignored, dismissed. A mother ALWAYS knows when something is not right with her child. Listening to a parent saves lives." [8].
- "Noah was treated appropriately for dehydration, but no one considered that there were other possible complications. I was not considered a partner in Noah's care. There was not a lot of thought given to the concerns that I raised as his mother." [9].

The care of children in general hospitals has been surveyed via the Health and Human Services Partnership for Patients Campaign [10], which has determined that many staff are not adequately trained on pediatric care in community

hospitals. Many of us are aware that children are not little adults and their care needs to be tailored appropriately and safely with trained and experienced staff. Sometimes, that does not occur.

Partnerships will help bolster that lack of training. "Participation in shared decision making was cited most frequently as the recurring role of patients and families on the team. This role was noted most in primary care settings; hospitals, clinics, hospice, and community practices; and among patient-centered health care teams" [11].

Parent and family partnerships have created new and exciting endeavors to improve pediatric care in the past 10 years. All of those efforts are born out of a desire to ensure other parents do not have to experience what they have gone through. Parents' efforts to develop and promote safer care have been arduous and the results slow at times [12]. Yet, great strides have been made toward improving pediatric health care for the better [13].

"And the day came when the risk to remain tight in a bud, was more painful than the risk it took to blossom."—Anais Nin

Gaps in communication with adolescents

The majority of patient complaints, near misses, and critical incidents center on communication deficits, both between healthcare professionals and between healthcare professionals and patients [14]. This is supported by a qualitative questionnaire survey of parents, children, and doctors around the world, administered by the Paediatric International Patient Safety and Quality Community (PIPSQC) Ambassadors' Network [12].

Among the survey results, communication and involvement were rated high by both physicians and patients. The most negative experiences came in moments of poor communication and administrative issues, and the more positive experiences were recorded when doctors and patients worked together, and families were involved. Doctors expressed a desire to improve communication and be more focused on their patients, without distractions. It appears that doctors recognize the overwhelming need to partner with parents and families, but the challenge remains in putting this into practice [15].

The drive to improve communication with children and families has resulted in PIPSQC initiatives to engage parents and children in their own care as much as possible. PIPSQC Ambassadors have recruited help from adolescents, using focus groups and surveys, to try to understand how they would like us to communicate and how they would like to be involved. Adolescents have also been involved in designing questionnaires for their peers, so surveys effectively phrase the right questions. They have also been involved in anonymous data analysis and have shared their perspective on the PIPSQC blog [16].

In a recent global teenage patient survey, initial responses to the nascent study spoke volumes. Many respondents felt the medical staff listened to and involved them as part of their own treatment team. Positive experiences included "A nurse who was very friendly... and made me feel happy during my experience here;" and "That I got put to sleep, woke up feeling great and that my friends got to see me." It is important to understand what matters to children

and try to facilitate this whenever possible. When asked if they would change anything about the care they received, here were some of their responses:

- “When I was diagnosed, I wish they’d let me sleep more overnight. I was woken up lots for testing and injections. They tried explaining things to me overnight but I was too tired to concentrate.”
- “More personal care.”
- “Don’t give my family so much stress because of my illness.”

The study demonstrated a need for improved communication around discharge instructions and follow-up care. Several children asked for more information on what came after the hospital care. When asked how they would like things to improve, examples of their suggestions were the following:

- “Give aftercare information and clear instructions for what to expect at home.”
- “Predict unforeseeable events that may happen and tell us what to do if they happen.”
- “Make sure both parents and child have no concerns/reasons to be anxious when they leave.”
- “Listen to me and talk to me directly even though I was deaf.”

It appears that although doctors complete written discharge summaries and may communicate plans to parents, they frequently forget to communicate discharge plans to children directly. It is extremely important that we strive to correct this gap in communication, especially for adolescents who should be encouraged to increasingly take responsibility for their own health care.

Many teens with disabilities are becoming more aware and interested in finding a cure for their specific condition or creating a tool to help them live more fulfilled lives, while also helping other kids in their situations. With their involvement in social media and technology, they are the ideal teachers and healers of the future. Parents of a sick child are similar. They research and learn whatever they can, hoping for a cure for their child’s disease or some new development to help their child. “This field (Technology), from when I started 15 years ago until now, has really seen an attraction of younger people wanting to get involved,” says Alex Mihailidis, a University of Toronto professor who holds a chair in rehabilitation technology [17].

Overall, children are trying to highlight the need for doctors to communicate directly with them. We also have shown that with support, some adolescents are keen to get involved in quality improvement and offer valuable insight. Partnering with children and families should be central to every quality improvement initiative.

Bereavement and coordination of aftercare

The death of a child is a time of unparalleled grief and vulnerability.

When a child dies, usually death happens in the PICU. An aftercare program or ways to comfort the family and the providers immediately following such a tragic event can create an everlasting bond. After researching various

bereavement programs, we have found programs from which hospitals could learn and expand, in the name of family-centered care.

Many families speak of being left in a room all alone or merely being sent home with an old plastic bag full of their child's belongings never to hear from the hospital team again. There is no empathy, no resources to help with grief, no memorial services provided, no counseling or clergy, and no card. The feeling of abandonment is very real.

Finally, another story from a nurse in California. She and her care team cuddled a dying child with favorite blankets. Hand in hand with the family, the physicians, nurses, child life specialists, and chaplains carried the child outside to die under a beautiful magnolia tree on the hospital grounds because that was the parents' wish. The entire team did what mattered to the family and the child died in peace. It did not take any more effort for the clinical team and they will remember the experience forever. Perhaps the memory will help instill more empathy in their daily parent encounters. Residents, who often do not show their vulnerability, might also see the death of a child more clearly through the parents' eyes. They can understand the value in allowing their humanity to appear during all their patient interactions. That emotion honors both the family and the clinicians themselves.

The practice of students and clinical teams not mentioning or acknowledging that a child under their care died needs to end. There is more to the death than any may realize. Empathy and kindness must abide with a coordination of aftercare to support tragedy and loss. It seems only reasonable to have those centers of healing provide resources for the families who perhaps had never experienced tragedy or death before, and who are faced with this other world of sorrow, sometimes at the hands of the healthcare team, in which they have no idea how to survive.

Creating a bereavement and palliative care team should be easy. Family members working through the grief process would be able to assist. Most would be more than willing to honestly share their experiences. We have interviewed care teams at Boston Children's, Cincinnati Children's, Dana Farber, Good Samaritan Hospital, Greenville Children's, Gundersen Health, Primary Children's, Rady Children's, and many others that have created programs that provide care after the loss of a child. The families gave positive feedback that the hospital experiences supported their needs and validated the feelings associated with the agonizing loss of a child [18].

Thankfully, many Children's Hospitals are now leading the way with "safety nets" of care and support for their families [18, 19]. New standards of care for those caring for children in all hospitals are sure to be on the horizon as well as guidelines for community hospitals requesting pediatric care.

Allowing parents to create memories and embrace support during difficult conversations from a whole team can comfort families. Our research with parents and families found that there was great concern for the impact on the siblings of the deceased child. The parents, often too distraught to care for them emotionally, needed assistance from the care community. The death of a child affects hundreds in the community. The Compassionate Friends international family support group is one excellent resource that many hospitals refer families to [20]. Disease-specific support groups on Facebook and websites also have comforted many sharing their stories, concerns, and personal research. The

connection with someone who has experienced your pain, and who is willing to communicate, can be vital to one's healing process.

Conclusion

Clinicians who demonstrate a family-centered approach to medical care are better positioned to create empathetic and collaborative partnerships. Using the lens of quality improvement will lead to improved medical outcomes, increased patient safety, and a decrease in the emotional detachment of the care team. As we become a more open medical community, the rewards for the children will be unparalleled, and we will reinforce the reason why we selected health care as our career.

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Compliance with Ethical Standards

Conflict of Interest

Dale Ann Micalizzi declares that she has no conflict of interest.

Hannah Zhu declares that she has no conflict of interest.

Thomas Dahlborg is an Advisory Board Member for the Center for Health Engagement, an Advisor to the Patient Voice Institute, a Health Equity Advisory Council Member for the Daniel Hanley Center for Health Leadership, and is guest contributing writer for Hospital Impact, FierceHealthcare and other publications.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

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