

The Heart of Health Care

Parents' Perspectives on Patient Safety

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KEYWORDS

- Patient safety • HEART model • Service recovery • Medical error • Patient harm
- Healthcare quality

KEY POINTS

- Today there is no lack of discussion about health care delivery and quality.
- Quality from the parent's perspective includes access to care, responsiveness and empathy, good communication and clear information, appropriate treatment, relief of symptoms, improvement in health status, and safety and freedom from medical injury.
- If a medical injury occurs it is important to listen to the parent, acknowledge the damage, give an honest and open explanation and an apology, acknowledge anxieties about future treatment, and provide practical and financial help quickly.
- Nursing shortages, overtime, financial obligations, and insurance company guidelines interfere with the quality of care.
- Work as a team, review all the information, establish a plan, communicate between specialists, remove arrogance and intimidation, and have a common goal to heal.

AUTHORS' BACKGROUND

Dale, a childhood educator in New York, is mother of Dan, Andrea, and Justin and grandmother to Isabella. When Justin was 11 years old he underwent minor surgery on his ankle. During the procedure, something went terribly wrong and Justin's heart arrested. Justin was urgently transported from the surgical hospital to a pediatric intensive care unit where Dale and her husband experienced every parent's worst nightmare: the preventable loss of their loving, healthy child. Error on error killed Dale's son and her faith in a medical system that was meant to comfort and heal. Determined not to let this unbearable pain happen to another family, Dale has spent more than 10 years working with the health care sector, trying to reduce the fear and secrecy that surrounds adverse events. As part of this endeavor, Dale founded the Justin's HOPE Project at the Task Force for Global Health.¹ Justin's HOPE, in partnership

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with the Institute for Healthcare Improvement, provides yearly scholarships to health caregivers who are committed to patient safety and providing a safe health care environment for patients and their families.²

Marie has three children (Finn, 12; Stella, 10; and Zoe, 8) who have experienced the usual spectrum of childhood bumps and illnesses while living in New Zealand, Australia, and the United States. For the last 10 years Marie has worked in the field of patients' rights and complaints resolution, including 4 years as an advisor to the New Zealand Health and Disability Commissioner and a year as a Harkness Fellow at the Harvard School of Public Health. Marie currently works as a Senior Research Fellow at the University of Melbourne researching the influence of patients' complaints on quality and safety of health care.

INTRODUCTION

Health care providers that encourage patients and parents to be "the eyes and ears" of patient safety gain many insights into opportunities for improvement and risk prevention.³ Yet, in the world of quality improvement the voices of patients and their families often go unheard. As mothers of children who have benefited from and been harmed by pediatric care we are grateful for this opportunity to share our perspectives on patient safety.

Our views are informed by our personal experiences, and enriched by conversations and written communications with hundreds of families. Many of the parents we have spoken with lost not only a child, but also their trust in medicine as a result of a senseless and preventable medical error.

As they were administering the anesthetic to James he looked at the anaesthetist and said "don't hurt me." Those were James' last words.

Others recall extraordinary care and moments of compassion as doctors partnered with them to provide their child with the best possible care.

It is the memory of one act that still brings tears to my eyes. In the junction between hospital buildings there is a join in the floor. This caring nurse stopped Chloe's trolley and individually lifted each wheel over the join to prevent her broken neck from being jolted. Compassion is revealed in the smallest acts.⁴

There is no substitute for being present with these families as they recall their experiences of pediatric health care: the good and the bad. To communicate some of their sentiments and suggestions with the reader, we have woven their words within this article wherever possible. Through different yet connecting eyes we offer the parents' view of patient safety and share our hopes for the future.

This article is arranged in five sections, which correspond to the five parts of the HEART model for service recovery: *Hear, Empathize, Apologize, Resolve, and Thank*. Variations of this model are used within^{5,6} and outside⁷ health care by front-line staff who seek to resolve problems by putting the needs of the affected person first.

SERVICE RECOVERY AND THE HEART MODEL

As parents, we do not expect perfection. We understand that people make mistakes and we understand that no part of life is entirely free from error or harm. However, we do expect that systems are designed with safety in mind and that when things go wrong someone steps in quickly to fix the problem. Unfortunately, health care performs poorly on both counts compared with other industries with stronger cultures

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