

Michael A. DeVita · Ken Hillman
Rinaldo Bellomo *Editors*

Textbook of Rapid Response Systems

Concept and
Implementation

Second Edition

Mandy Odell
Daryl A. Jones
Bradford D. Winters
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Associate Editors

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Since we have started work in this field, we have met many fantastic clinicians who have worked to improve our knowledge and application of Rapid Response Systems. They are amazing. However, the greatest and most heartfelt impact the editors have encountered is the children, parents, siblings, and spouses who have lost their loved ones due to the failure of a hospital system to respond effectively to deterioration. They have shared their pain with us, and we remember them daily. This textbook is dedicated to the lost loved ones.

Preface

Over 20 years ago, physicians and nurses in separate regions of the globe started work to reduce cardiac arrests by reorganizing healthcare delivery systems. The novel process involved identifying patients who were deteriorating and developed critical illness outside the ICU. Subsequently a response team was notified or “triggered” in later terminology, and these multidisciplinary professionals brought clinical and equipment resources to the bedside very quickly. While they did not supplant the “home” care team, they did augment it by enhancing the resources brought to bear to prevent further deterioration, cardiac arrest, and death. The results were impressive, but because the early studies were before and after trials, the quality of the data was judged by many to be poor and the results inconclusive. Their emphasis on the team response was significant and a controversy of sorts developed over what was the best response team. The first of two consensus conferences allowed these investigators to “compare notes.” As a result, they concluded that the team response was only one component of a four-part system, which was named the Rapid Response System (RRS). The second conference reflected the growing appreciation by most investigators that the whole system did not work unless it was reliably “triggered.” Without the trigger, there could be no response. Since this report, many investigators have continued to work on this afferent limb of the RRS. Our first two books in this field reflected these two modes of thinking, although we did try to demonstrate how the RRS could be adapted to many other critical and time-sensitive situations in the hospital setting. We devoted many pages in both books related to defining the characteristics of the system, how to create one in hospitals naïve to the process, and how to both improve and expand the process in more experienced settings.

In this third book, the second edition of the Rapid Response Textbook, we have tried to again capture the major trends in RRS implementation and modes of thought. At the 13th annual International Meeting on Rapid Response Systems and Medical Emergency Teams, the new International Society for Rapid Response Systems had its third general meeting. The Society has grown from 15 people in a room in London to well over 100 members from almost 20 countries. The meeting had almost 600 attendees. At this time, some form of RRS (although not named this way in all countries) is required in all or part of about ten countries around the world, and it is becoming more common in many other countries. Indeed, we feel that the

RRS in a sense is becoming an integral part of how acute hospitals function. And the demonstration of its effectiveness is becoming more obvious.

At this 13th meeting, we were struck by an interesting coalescing of data. Initially, in-hospital cardiac arrest rates were between two and eight per thousand admissions. Virtually all organizations implementing RRS effectively, meaning an RRS rate of greater than about 40 per 1000 admissions, showed decreased mortality. However, at this meeting, not one presentation now notes a cardiac arrest rate above 1 per 1000. Thus, in the decade and a half since our first meeting, there has been a one log improvement. This is a stunning achievement and it mirrors the improvements in safety initiatives in the airline industry and automobile industry. The change in scale from 0.6/1000 to 6/10,000 may be confusing at first, but it will serve to reset our frame of vision.

This prompts us to ask, “How low can in-hospital cardiac arrest rates go?” We are not sure of the answer to that, but we do have some thoughts on the matter. First, we would like to distinguish between cardiac arrest responses on the one hand and in-hospital death events on the other. Patients who might live have vital sign abnormalities that are the same as those of patients who are dying. Many patients in hospital are in fact dying naturally and expectedly from their underlying disease. As many as 1/3 of Rapid Response events are triggered for patients who are dying and expected to die. Most of these patients are more in need of palliative care to help promote a safe, painless, and comforting dying process. While some have decried the use of the RRS for patients who are dying, we support it if the patient’s death is “out of control” due to pain, distress, or inadequate preparation. We believe that the RRS trigger may be an opportunity to introduce palliation into such patient’s care plan. Because of this, we advocate promoting either palliative care skill sets for responders or a close linkage between the RRS and the palliative care team. With this in effect, cardiac arrest rates could drop by perhaps 30% due to implementation of “not for resuscitation” orders, some of those occurring at or after an RRS event. Second, better triage of hospitalized patients to special care wards may help. More effective triage may be possible through the use of better predictive tools using any one of a variety of severity scoring systems designed to find patients likely to die in the next few hours or days. Patients with elevated risk can have additional resources to bear. Indeed, some investigators have designed systems to not only provide risk estimates but also give decision support to bedside clinicians to promote better care management. Some tools go so far as to alert managers to clusters of high acuity patients. Knowing where (unexpectedly) sick patients are can enable moving resources to up-staff stressed units. These interventions have been shown to help as well, and their use is likely to spread. As they do, expect cardiac arrest rate to fall.

The third intervention which is starting to gain some momentum is continuous physiological monitoring. We are not talking about continuous ECG monitoring which does not signal well early signs of deterioration. We are focusing instead on the continuous monitoring of one or more of the following: heart rate, respiratory rate, level of consciousness, oxygen saturation, and exhaled carbon dioxide. Deterioration of any of these portends

trouble. Intermittent monitoring has been used on the general floors of acute hospitals for over a century. However, today's patients are sicker and have more complex interventions which can increase risk of unexpected and sudden deterioration. The unexpected death rate in hospitals among those who are selected high risk and who are monitored is not very different from "healthier" patients selected to not have monitoring. This begs the question of what likelihood of deterioration is sufficiently low to decide to not continuously monitor someone. Because we can never perfectly predict the future, until there is the ability to detect deterioration as it occurs, there will always be unexpected and tragic deaths.

So our answer to the question of "how low can the cardiac arrest rate go?" is "Zero." We feel it is time to target zero cardiac arrest responses in hospital (even though hospital death rates will never fall that low because as we noted, some people are dying from incurable and irremediable illness). We are looking for zero preventable deaths. We are a long way from that goal, but keeping that goal in mind was helpful in other safety initiatives that we would like to emulate.

There are barriers to even aiming for zero. First, the culture change needed to get clinicians to believe that it is a realistic target. Second, the continued change in hospital staffing to enable RRSs to flourish is not easy in some organizations. Additional data and examples from forward thinking hospitals may lead such organizations to progress. A third barrier is cost. Continuous monitoring is expensive, and most hospitals simply cannot see their way to finding the money to invest, let alone consider the return on investment. Fear is another barrier. Some of us have found that some clinicians are more afraid of being blamed for not responding to an alarming monitor than they are of the consequences for the patient of that action. This is a startling observation, but this type of fear of failure exists in all of us to some extent.

There are promoters as well. All clinicians have experienced the situation when they have had to interact with the family of a patient who was not supposed to die. These tragedies impact the clinician in profound ways that may be different and less tragic for the patients themselves and their family, but which are tragic and life altering nonetheless. Some clinicians have left healthcare as a result.

We think the advances in safety that the RRS is promoting will continue to spread and become better. We hope that our textbook is moving beyond the simple introduction of the system and providing resources that can be used to target zero.

The first chapter of the textbook is important. In it, Helen Haskell puts a very personal face on the need for the RRS. These stories moved us so much that we felt they needed to be the first thing the reader of this textbook sees. It will impact in a way that mere numbers cannot. The remainder of the first section is devoted to the patient safety system and the place of RRSs in building the business case and promoting culture change. The second section is geared towards how to create or improve the system. And the final section is focused on assessing the impact and educational interventions to support system improvements.

With the tools in this book, we hope that we will not only help you improve your hospital's safety but also help you to imagine a hospital with a zero cardiac arrest and zero preventable death rate.

New York, NY, USA
Liverpool BC, NSW, Australia
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Michael A. DeVita
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Contents

Part I RRSs and Patient Safety

| | | |
|-----------|---|------------|
| 1 | Why Have a Rapid Response System? Cold with Fear: The Patient and Family Experience of Failure to Rescue | 3 |
| | Helen Haskell | |
| 2 | Rapid Response Systems: History and Terminology | 17 |
| | Bradford D. Winters and Michael A. DeVita | |
| 3 | RRS's General Principles | 25 |
| | Ajay D. Rao and Michael A. DeVita | |
| 4 | Measuring Safety | 31 |
| | Bradford D. Winters, Peter J. Pronovost, Marlene Miller, and Elizabeth A. Hunt | |
| 5 | Medical Trainees and Patient Safety | 45 |
| | Stephen Lam and Arthas Flabouris | |
| 6 | RRS and the Culture of Safety | 53 |
| | Ken Hillman, Hadis Nosrati, and Jeffrey Braithwaite | |
| 7 | Creating Process and Policy Change in Healthcare..... | 59 |
| | Stuart F. Reynolds and Bernard Lawless | |
| 8 | The Assessment and Interpretation of Vital Signs | 63 |
| | John Kellett | |
| 9 | Multiple Parameter Track and Trigger Systems..... | 87 |
| | John Asger Petersen | |
| 10 | Causes of Failure to Rescue..... | 95 |
| | Marilyn Hravnak, Andrea Mazzoccoli, Eliezer Bose, and Michael R. Pinsky | |
| 11 | Rapid Response Systems: A Brief Review of the Evidence | 111 |
| | Bradford D. Winters | |
| 12 | Making the Business Case for a Rapid Response System | 125 |
| | Shane C. Townsend | |

Part II Creating an RRS

| | |
|---|------------|
| 13 Hospital Size and Location and Feasibility of the Rapid Response System | 139 |
| Daryl A. Jones and Rinaldo Bellomo | |
| 14 Barriers to the Implementation of RRS..... | 147 |
| Oluwaseun Davies, Michael A. DeVita, and Ken Hillman | |
| 15 An Overview of the Afferent Limb..... | 159 |
| Gary B. Smith, David R. Prytherch, and Alex J. Psirides | |
| 16 The Impact of Delayed Rapid Response System Activation | 173 |
| Daryl A. Jones, Christian Subbe, and Rinaldo Bellomo | |
| 17 Nurse-Led Rapid Response Teams | 181 |
| Kathy D. Duncan, Terri Wells, and Amy Pearson | |
| 18 MET: Physician-Led RRTs | 193 |
| Daryl A. Jones and Rinaldo Bellomo | |
| 19 Pediatric RRSs..... | 201 |
| Christopher P. Bonafide, Patrick W. Brady, James Tibballs, and Richard J. Brill | |
| 20 Rapid Response Systems and the Septic Patient..... | 213 |
| Patrick Maluso and Babak Sarani | |
| 21 Other Efferent Limb Teams: Crises that Require Specialized Resources | 219 |
| Dan Shearn, Francesca Rubulotta, and Michael A. DeVita | |
| 22 Crisis Teams for Obstetric Patients..... | 229 |
| Patricia Dalby, Gabriella G. Gosman, Karen Stein, David Streitman, and Nancy Wise | |
| 23 Personnel Resources for Responding Teams | 241 |
| Sonali Mantoo, Michael A. DeVita, Andrew W. Murray, and John J. Schaefer III | |
| 24 Equipment, Medications, and Supplies for a Rapid Response Team..... | 253 |
| Edgar Delgado, Rinaldo Bellomo, and Daryl A. Jones | |
| 25 Governance of the Rapid Response System..... | 267 |
| Melodie Heland and Daryl A. Jones | |

Part III Monitoring of Efficacy and New Challenges

| | |
|---|------------|
| 26 Continuous Monitoring for Early Detection of Deterioration on General Care Units..... | 277 |
| Magnolia Cardona-Morrell, Eyal Zimlichman, and Andreas Taenzer | |

| | |
|--|-----|
| 27 Dying Safely | 289 |
| Magnolia Cardona-Morrell and Ken Hillman | |
| 28 The Second Victim | 301 |
| Susan D. Scott, Laura E. Hirschinger, Myra McCoig, Karen Cox, Kristin Hahn-Cover, and Leslie W. Hall | |
| 29 Rapid Response Teams in Teaching Hospitals | 309 |
| Max Bell and David Konrad | |
| 30 The Nurse’s View of RRS | 315 |
| Mandy Odell, Nicolette Mininni, and Donna Goldsmith | |
| 31 Opportunities for Resident Training with Rapid Response Systems | 321 |
| Geoffrey K. Lighthall | |
| 32 Optimizing RRSs Through Simulation | 329 |
| Melinda Fiedor Hamilton, Elizabeth A. Hunt, and Michael A. DeVita | |
| 33 Evaluating Effectiveness of Complex System Interventions | 341 |
| Jack Chen | |
| 34 Rapid Response Systems: Education for Ward Staff Caring for At-Risk and Deteriorating Patients | 351 |
| Gary B. Smith and John R. Welch | |
| 35 Setting Up a Standardized Process and Outcome Assessment Tool | 367 |
| Gabriella Jaderling and David Konrad | |
| 36 The Impact of Rapid Response Systems on Not-For-Resuscitation (NFR) Orders | 375 |
| Arthas Flabouris and Jack Chen | |
| Erratum to: Dying Safely | E1 |
| Index | 383 |

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Part I

RRSs and Patient Safety

Why Have a Rapid Response System? Cold with Fear: The Patient and Family Experience of Failure to Rescue

Helen Haskell

In this textbook, many authors will present data supporting the impact of rapid response systems and provide guidance for how to create or improve an organization's rapid response system. This chapter is different. It is intended to provide insight into the *human* impact of failing to rescue patients who have serious deterioration while in hospital. The stories in this chapter provide poignant testimony on why rapid response systems must exist. In addition, they will help the reader understand why patients and families should be allowed to activate the system.

As is noted elsewhere in this textbook, the 2014 review by Sir Liam Donaldson and colleagues of the recent National Health Service incident reports finds "mismanagement of deterioration" to be the single most frequent category of preventable death [1]. This well-known but disturbing phenomenon is doubly confounding since not only clinicians but also friends and family are often in attendance as a patient spirals downward. Patients and families are usually well aware when a patient's health status has gone awry, and most feel free to express their concerns to bedside nurses and doctors. Yet families frequently report that their concerns are not heeded [2]. In such situations, few people feel on sure enough ground to try to override the decisions of

medical personnel, and fewer still would know how to do so even if they were confident. What happens to those patients and families who are not rescued? How do these crises play out in the eyes of the family? And what do families see as the solution? Below are four stories from the family member's point of view, beginning with the one I know best, that of my own son, Lewis Blackman.

Lewis's Story

In November, 2000, I was the mother of two high-achieving and to my eyes appealing and well-behaved children, Lewis, 15, and Eliza, 10. Our lives were the usual hubbub of childhood activities and we looked forward for the next number of years to the fixed trajectory of high school and university, the only variables being which universities and where their studies should be focused. Our children were excellent students and the choice was theirs.

Then my husband and I made a fateful decision. Our son Lewis had an indented chest wall, a mild but clearly noticeable case of pectus excavatum. After reading a newspaper article extolling a safe, minimally invasive new surgical repair, we consulted with a pediatric surgeon at a nearby teaching hospital. As it was our understanding that this surgery was best performed before maturity, we determined to proceed before his bones had "hardened." I am ashamed to think how little

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concern we had about an operation whose seriousness we did not really understand.

Nevertheless, we entered the hospital, as any sensible person does, with trepidation. It is almost unbearable now to think how frightened my son was, though he put on a brave front and his fears were probably only evident to me. His history was taken by a young woman who a few minutes later reappeared wearing a large badge reading, "INTERN," a piece of information that would prove helpful to us later. Other than the intern and a cheerful anesthesiologist in a funny hat, we did not know the roles or identities of anyone in the maelstrom of people who swirled around us.

Though we could not really know, we had no reason to believe that Lewis's surgery did not go well. The problems began afterward. In the recovery unit, Lewis was not urinating. The urinary catheter was suspected and changed, to no effect. Eventually he was discharged, still not urinating, to a room on the hematology-oncology floor. No surgical beds were available.

We had been in hospitals before, but never in a teaching hospital. We were baffled at the lack of attention to our concerns. The intern materialized, now minus her badge. We showed her the empty urine bag and she ordered a bolus of saline solution. Familiar only with the Latin, we puzzled as to why our son was being given "balls" of fluid, eventually concluding, more or less correctly, that it meant simply "a large amount."

We limped through the night and most of the next day on boluses, every one of them initiated by my husband or me. The underlying problem was apparently a reluctance to change the erroneous order that had been written in the post-anesthesia unit by the chief resident, though we only discerned that much later. There was no indication that anyone but us ever gave much thought to the lack of urination or to the effect it might have on the many medications our son was taking. The problem was finally solved on the second day after surgery, when an experienced nurse and a pharmacist teamed up to get a junior resident to write a new order. When Lewis finally began urinating at the end of the day, we thought it was a triumph.

For pain relief, Lewis was on epidural hydro-morphone and bupivacaine, supplemented by 6-hourly injections of the NSAID ketorolac. At 120 pounds, he was barely within the minimum for the adult dose for ketorolac in the USA, though its use was still off-label due to his age. His pain continued to worsen and the amounts of epidural analgesics, not inconsiderable to begin with, crept continually upward. We still had not learned the identities of the many uniformed people streaming in and out of our room, but we were finding the confusion increasingly disconcerting. We could see that the staff were not communicating about their patients and were giving off-the-cuff opinions that sometimes seemed no more than bluffing.

The weekend arrived, the hubbub subsided, and the hospital fell quiet. The on-call attending rounded on Saturday morning and we did not see him again. Lewis was nauseated, sweating, and itchy, as he had been since day 1. While he didn't get better, he didn't get worse. We lacked the tools to judge, but it was clear he was not going home on Monday as had originally been suggested.

Instead, at 6:30 a.m. on Sunday morning, he was stricken with a sudden new, inexplicable pain in the area of his stomach, quite separate from his surgical pain. This transpired half an hour after a ketorolac injection and in the midst of a shift change. On the children's pain scale, Lewis said in panic, it was 5 out of 5, or more. The night nurse, not yet off duty, answered our call with alarm. A few minutes later she was back with the reassurance that this was "only" an ileus, caused by the narcotics in his epidural.

Thus began the last 30 h of our son's life. The train wreck of his medical care during those hours derived in no small part from that bland assessment, which appeared in retrospect to have had its genesis in nothing more than chatter in the nurses' station. Whatever its origin, the label of "ileus" stuck like a burr, even as Lewis's symptoms made it ever more unlikely to be correct. His pulse and respiration rates gradually rose and his temperature dropped. His blood pressure rose, then fell. Urination again ceased. His eyes became huge black circles, like Franklin

Roosevelt in the weeks before his death. His pain, undiminished, migrated from the epigastric area to his lower abdomen. His belly swelled like a watermelon.

The day nurse stuck to her guns. Today was the day Lewis was supposed to get out of bed and with much assistance he did. From the chair Lewis said, "This was a mistake." Thinking of the whole surgical undertaking, I fervently agreed. But he was focused on the immediate; he was thinking of the logistics involved in getting back in bed and the agonies of vomiting sitting upright with hardware in his chest. Later the nurse said that Lewis should walk to ameliorate his ileus. Since he was too weak to stand, we half-supported, half-dragged him around the ward, stopping every few steps so Lewis could lean on me to rest.

Most of the time, however, Lewis and I were left to our own devices. The nurses were preparing for an inspection the following day and seemed energized by the distraction. When I ventured out of the room I found the silverware rearranged in the kitchen and cheery crayon pictures drawn on the windows. Even our doorplate had been polished. It was a thousand miles away from our universe of pain and fear on the other side.

The nurses seemed unable to see what I was seeing: that my son was going into shock. I had only a vague idea what shock was, but I thought I remembered the symptoms from a junior high First Aid class 35 years earlier. I was very uncertain. I wanted to call Lewis's surgeon, but I did not think anyone would be there to answer the phone in an academic department on a Sunday. I would have liked to go over the head of Lewis's nurse, but I never imagined there might be a supervisor present in the hospital. Our world was the bedside nurse, and I felt helpless to get around her.

Throughout this long day, I had asked repeatedly for a doctor. I did not mean the intern, though I eventually came to suspect that her intermittent visits might have something to do with my requests. I tracked down Lewis's nurse in the break room. She said, "You've just seen the doctor!" Had the intern not been labeled for the OR back on day 1, I would have been thrown into

confusion. Instead I said, "I want a real doctor, not the intern!" I asked for the attending physicians by name. Grudgingly, she agreed to call.

More hours went by. That evening a young man came to Lewis's room. Although I did not know it, he was the same resident who had misprescribed Lewis's IV fluids 3 days earlier. He was wearing a jacket and brought with him a whiff of cold air: although Lewis had entered the hospital wearing shorts and sandals in the warm South Carolina fall, winter had arrived while we were there. The young doctor affirmed the diagnosis of ileus. Lewis's other alarming symptoms, he said, were due to opiate naiveté. Although this explanation left many unanswered questions, I acquiesced. I assumed he was the attending physician I had requested and I thought that if all the nurses and doctors were saying the same thing, they must be right. It never occurred to me that they might all be following each other down a single path.

The story becomes sadder. Around 6 a.m., Lewis's pain vanished, as suddenly as it had come. Lewis and I were disconcerted at this abrupt change, but the team of residents and students who happened by at that moment said, "Oh, good!" 2 h later, the vital signs technician could not detect a blood pressure. Again, no action was taken, because the residents had reported his pain improved, because he showed no signs of cognitive impairment, and because the surgeons were all occupied in the operating room. The lack of BP was attributed to faulty equipment.

By late Monday morning, Lewis's pulse rate peaked at 163. He had lost, we later discovered, 11 pounds. He looked like a small white skeleton in the bed. His father, little sister and I were all in the room, cold with fear as we waited for the doctor to arrive and save the day. Technicians came and went, conducting tests that had been deferred from the night before. While having his blood drawn, Lewis went into cardiac arrest. The code lasted over an hour and the code list included around 20 people. They could not revive him.

The five surgeons who announced his death to us were the first attending physicians we had seen in over 2 days. It was from them that we learned

that the doctor we were awaiting had never been called; no one had seen it as an emergency. Though it was nearly more than I could bear, the on-call attending persuaded us to have an autopsy. To their surprise, the autopsy showed a giant duodenal ulcer, presumably associated with the ketorolac, and a blood loss of nearly 3 L. via the underlying eroded gastroduodenal artery. He was 15 years, 2 months, and 2 h old. It was a very casual end for a beloved child, who 5 days earlier held the world in his hands.

These events happened many years ago now. If Lewis were alive he would be a grown man. I have spent nearly every minute of the intervening years working on patient safety, my expiation for failing in the one fundamental duty of a parent. There are few corners of patient safety and quality into which I have not ventured, because there are few errors that were not touched on in his care. But for me the central issues have always remained rapid response and failure to rescue. Our first effort was state-level legislation: the Lewis Blackman Hospital Patient Safety Act, which passed the legislature in our state of South Carolina in 2005 [3]. It was focused squarely on failure to rescue and related issues in Lewis's care. Among its provisions: clinicians were to be identified, with residents labeled as such; patients were to be allowed to speak directly to their doctors and not just through intermediaries; and most important to me, patients were to be given an emergency "mechanism" they could trigger in case of unaddressed medical concerns. This was the most contentious part of the bill, not so much because hospitals objected to the call system as that they were concerned about the implications of telling patients why it might be needed. The law passed unanimously, in part because South Carolina legislators were surprised that these protections did not already exist.

As the years have gone by, we have become more involved with national and international policy. I have seen many reforms and much change in attitude. The question I ask is how much things have really changed for patients. The answer seems to be that much has changed and much remains the same.

Noah's Story

Around the same time Lewis died, 4-year-old Noah Lord had a tonsillectomy for what his surgeon erroneously believed was obstructive sleep apnea. The surgery took place on a Friday morning. For 2 days after he was discharged, Noah was lethargic, was vomiting, and would not eat. Finally, on Sunday morning, Noah's parents took him to the emergency room, where he was treated in the extended emergency department with intravenous fluids for dehydration and IV morphine for his pain. Noah's mother Tanya picks up the story:

His pain improved, but he still was not eating or drinking the entire time he was in the emergency department. The ED staff tried to entice him with slushies and popsicles—anything they could think of, but he wouldn't eat anything. He was extremely lethargic and I was concerned, but they told me that the morphine was making him groggy and it was to be expected.

Noah developed a cough that sounded like he was clearing his throat all the time. I went to the nurses' station to ask if this was normal and was told that this was okay and "not to worry." They were not ED nurses but covering nurses from obstetrics.

While in the ED we saw a variety of different surgeons and nurses but were never really sure who was in charge as they were not identified and often neglected to introduce themselves by name. The surgeon who performed Noah's surgery consulted by phone—and never showed up to examine Noah.

At one time, a woman came in and I grabbed her by the wrist and pulled her over to the bedside and said, "He really is not doing well." I asked the woman to just look at him to help me and she responded, "I am really sorry, but I am just here to take the dirty laundry." At one point an older

gentleman poked his head in and said, “How’s it going in here?” I responded automatically, “Okay,” and then the man disappeared. I found out later that he was the Emergency Department attending physician. I met with him 10 years later and he remembered poking his head in the room and walking away.

A nurse came in and announced that they had talked to Noah’s surgeon and that he wanted him sent home with an intravenous line (a peripherally inserted central catheter or PICC line) so he would be able to receive fluids at home. A visiting nurse would come to our home during the evening so Noah would sleep with an IV.

The nurse handed me a paper to sign and I signed it. This was Monday morning following Noah’s surgery on Friday. I was so exhausted that I just signed the paper without looking at it. The nurse left the room and I waited for about 3–4 h without anyone coming into the room. So I went to the nursing station again and I told them that I really wanted to talk to a doctor. The nurses’ response was, “You can’t talk to a doctor; you have been discharged.” This was the first time that I realized that the paper I had signed was his discharge paper [4].

Not knowing what else to do, Noah’s parents carried their son to the car and took him home, still vomiting. Several hours later, Noah began hemorrhaging from the mouth so profusely that it blocked his airway. His mother, a trained life-guard, was able to resuscitate him three times, but finally there was a clot she could not clear. By the time the ambulance arrived, Noah was dead.

His mother said, “My world ended the day he died. For years I have looked back on those 3 days and wondered what I could have done differently... Had they listened to me, not just the words I was saying but really taken a moment to see who I was as a person, I think they wouldn’t have missed so much” [5].

D.J.’s Story

In 2010, D.J. Sterner, a 47-year-old truck driver undergoing chemotherapy in the hospital, developed acute gastrointestinal distress, with vomiting and extreme pain that could not be controlled with morphine. Here is how his wife, Karen, described it:

The nurse told us that D.J. was just having anxiety, but we thought it was something more serious. His nurse gave him Ativan for anxiety [but] D.J. was in agony all afternoon. His breathing was very shallow, just a pant. We did not realize at the time how serious this was or we would have been out in the hall screaming for help.

Around 3:00 p.m. the nurses began trying to page the doctor to tell him that something was wrong... The nurses made seven calls approximately half an hour to an hour apart up until 7:00 that evening. The doctors never responded. Every time they were called, there was nothing. At one time a doctor who was called assumed that the other doctor had already been to D.J.’s room.

D.J. finally threw his hands up in the air and said, “That’s it. I want sedation.” I was very surprised because it was totally out of character for him to be complaining of pain. He told us he was scared. He even said to his nurse, “Please make it stop.” We knew something was very serious for him to be talking this way.

His nurse checked his respiration around 6:30 p.m. and it was around 20. Then they checked it again around shift change at 7:00 p.m. and it was closer to 30. His blood pressure was really low and his blood oxygen level was 43 percent. At that point his nurse paged another doctor overhead.

By the time the doctor arrived, D.J. had passed out. The nurse called a code and it took only *two minutes* for the resuscitation response team to get to the room. When the respiratory therapist walked through the

door she said to the assistant next to her, “I knew he was in trouble before I got through the door.”

The assistant replied, “Why didn’t they call us sooner?” [6].

Karen added, “It has been hard for me because he died in excruciating pain. That is the hardest part for me because I felt like it was unnecessary. I felt as though he was basically being dismissed. I felt as though, because he had leukemia, the hospital really did not feel like they wanted to help him” [7].

Curtis’s Story

On a Saturday morning in 2012, 65-year-old Curtis Bentley was admitted to an intensive care unit for bleeding following placement of a cardiac stent and a subsequent change in his anticoagulation regimen. His daughter, Annette, stayed by his side every minute until, awakened by a nurse at 4:00 a.m., she decided to take a much-needed break. Here is her account of the events that followed:

I stopped at the snack machine, called my husband, and sat for a while in the waiting room. While I was away from my father’s room, I heard a Code Blue sound. At first I thought it was for him, but it was for the neighboring patient. I sat a little while longer, but then I had an uneasy feeling. Something told me to go check on him.

I went back and saw that the Code Blue was indeed for the neighboring patient and that many physicians and nurses had responded. However, no one was with my father.

When I walked in, I couldn’t see my father’s face right away. One leg was hang-

ing out of the bed. Embarrassed, I asked him what was he doing, but he did not respond. I asked him a second time as I was covering him up. The TV went to a commercial at that moment and the light hit his face, which was down against the railing. He was positioned like he was trying to get out, perhaps trying to get help. When I looked closer, I saw that my father was taking his last breath. I knew immediately that it was his last breath, as my stepfather had died in my arms. Their last breaths were identical. I ran out calling for help.

A nurse came. During this time I’m yelling, “Where were you...where were you? Why wasn’t a code called for him?” She had no answer. I had been in the room with my dad. No nurse had been present. No machine had alerted them to his deteriorating condition.

My father was intubated and placed on life support. I found out by reading his medical records that he had gone into a coma, was brain dead, suffered paralysis and necrosis. No one at the hospital told me that. He was in a coma for seven days and he never came out of it.

A day or so after the code, I talked to the charge/manager nurse about what her staff had done (or rather not done) on that awful morning...I explained to her that there was no one around when my dad coded. No one was at the station monitoring him, nor any of the other patients for that matter—all except for the neighboring patient for whom the Code Blue had been called. The charge/manager nurse told me “Well, when our adrenaline gets going, our focus is on one patient.”

I took a deep breath. The tears started rolling. I asked her, “You mean to tell me, if you have 15 patients on ICU, they are going to go uncared for because your focus is on one patient?” She didn’t say a word. Then she said, “Somebody is supposed to be at the nurses’ station at all times” [8].

The Voice of the Patient

These vignettes reflect a miniseries of circumstances (pediatric hospital, cancer ward, emergency room, intensive care unit) and of patients (healthy children, cancer patients, the anticoagulated elderly). But common to all of them are the reactions of the families: shock, guilt, fear, and an overwhelming sense of helplessness.

A recurring concern among patients is fear of alienating caregivers by not being a “good” patient. Noah Lord’s parents carried their lethargic, nauseated son to the car because they felt trapped in the bureaucracy of discharge and, like most patients, were unprepared to violate the social conventions of courtesy in a situation they did not recognize as life-threatening. Noah’s mother expressed a common sentiment when she said, “I did not want to go home because I knew it was not the right thing to do, but I also did know how to push back and did not know what to say” [4].

At play is a combination of lack of knowledge and lack of status, with decisions arriving as fiat from a distant authority to whom the family cannot speak directly. The patient and family may feel disconcerted and disempowered, especially if, as is often the case, they lack medical knowledge and do not know how to navigate the hospital system. Family members feel the burden of their lack of knowledge keenly. D.J.’s mother said, “I wish I would have realized at the time how serious this was ... I am extremely angry and guilty that I did not realize more myself” [9]. D.J.’s wife Karen adds, “I did not know that we could go to the nurse’s superior. If I had known then what I know now I probably would have gone to the charge nurse and said, ‘The nurse has called or paged the doctors, but they are not responding. Is there anything else that can be done?’” [7].

Even healthcare professionals are thrown off base and begin to doubt their own judgment when the healthcare providers around them do not appear to be seeing what the professional family member finds obvious and frightening. Jonathan Welch, an emergency physician, recounts his shock upon arriving at the bedside of his mother who had been admitted to the hospital with neu-

tropenic sepsis. He says: “My mom’s emergency physician and oncologist had taken few, if any, of the essential and obvious interventions needed to save her life. The nurse seemed calm, as if everything was normal. What was their problem? Was I missing something? I felt trapped in an alternate reality where the medical rules were the opposite of everything I’d learned and practiced, where doctors and nurses were oblivious to impending disaster” [10].

Dr. Welch insisted on having his mother transferred to the intensive care unit. But as time went on and she continued not to receive needed interventions, he became more unsure:

I wish I’d done more at that point—raised hell, insisted on waking both my mom’s oncologist and the hospital’s intensive care doctor at home, demanded that they come to the hospital. Instead, by that point I felt lost and powerless... I knew there could be a downside to being too demanding in a hospital. I was losing my own confidence as a doctor, becoming instead the helpless son of a sick patient, someone who couldn’t get anything at the hospital to work [10].

As with our other stories, the ending is not a happy one. In desperation, Dr. Welch began working to transfer his mother to a different hospital. A new doctor brought on as part of that process finally began treatment but was unable to save his mother.

Patient-Activated Rapid Response

Overwhelmingly, the complaint from families is that their concerns are not heeded and their input not responded to. This is hardly limited to situations of patient deterioration; indeed, a striking feature of some medical stories presented in diary form is the sheer mind-numbing accumulation of minor and not-so-minor insults to the dignity and well-being of the patient, ranging from disregard

of hygiene to blind continuation of inappropriate treatments and delayed response to crises [11, 12]. But the consequences of this kind of disregard come most clearly into focus in failure to rescue cases. Especially in cases like those of Lewis Blackman, Noah Lord, or D.J. Sterner, in which patients deteriorate for hours as families ask repeatedly for help, dismissal of the patient voice can undeniably be a contributor to devastating outcomes.

To these families, patient-activated rapid response seems an obvious solution. Historically primarily a North American phenomenon, the idea of a patient-activated emergency system has been largely patient driven and is often presented as a patient “right,” even a civil right. Its spread can be credited to a mother, Sorrel King, whose 18-month-old daughter Josie, probably the world’s best-known failure to rescue victim, died from an undetected central line infection at Johns Hopkins in 2001. The Kings founded the Josie King Foundation and used part of Josie’s settlement to help fund early safety culture work at Johns Hopkins, raising the profile of their work with a widely disseminated video of Sorrel telling Josie’s story in a 2002 address at the Institute for Healthcare Improvement (IHI) [13]. In talking about Josie’s death, Sorrel emphasized the fact that Josie was not allowed to drink even though she was dehydrated, that Sorrel’s concerns about the child’s pallor and listlessness were dismissed, and that Josie’s cardiac arrest was precipitated by narcotics given in spite of the fact that Sorrel questioned them. Sorrel spoke movingly of the unthinkable experience of removing her child from life support and having Josie die in her arms, while “large snowflakes began falling slowly from the clouds above and the fiery sky turned them a pale pink, like nothing I had ever seen before” [14].

In December, 2004, Sorrel was onstage for a second time at IHI, standing at the end of a line of healthcare leaders from around the USA. The occasion was the introduction of the IHI’s groundbreaking Save 100,000 Lives campaign, which would, among other things, make rapid response a byword in American hospitals [15]. Sorrel was there to represent the patient voice, the first time a patient had so publicly been given

consideration as a healthcare stakeholder. When it came Sorrel’s turn to speak, she said, “Why can’t the patient push the button?” No real answer was given. But one person in the audience did take note: Tami Merryman, Vice President of Patient Care Services at UPMC Shadyside in Pittsburgh. She called Sorrel and asked for her help in establishing a system responsive to patients. Thus was born the patient-activated rapid response system known as Condition H [16].

The concept of patient and family activation was not new—it was implicit in the “emergency mechanism” of the Lewis Blackman Act and also in programs like the universal trigger of UPMC Presbyterian’s existing rapid response system, Condition C [17]. But UPMC Shadyside’s Condition H (for Help) gave patient-activated rapid response a structure it had previously lacked. Using the story and image of Josie King, Merryman created a complete system with formal triggering criteria (patients were instructed to call if they experienced a medical change not addressed by the health team, a breakdown in care, or confusion over their treatment), a two-tier screening system (a separate Condition H team assessed the patient before calling the rapid response team), a rollout plan, education strategy, and formal assessment tool [18, 19]. These materials were freely available on the Internet and were widely promoted by IHI, the Josie King foundation, and others [20–22]. While individual institutions could and did adapt it in many ways, the Condition H design would provide the basis for most subsequent patient-activated rapid response teams.

Uptake of patient-activated rapid response was buoyed by the Joint Commission’s National Patient Safety Goal 16A of 2008, which created the expectation that accredited organizations would “empower staff, patients, and/or families to request additional assistance when they have a concern about the patient’s condition” [23]. Promoted by patient advocates, the Joint Commission’s language was incorporated into the 2008 omnibus healthcare law of Massachusetts, making it the second state, after South Carolina, to require patient-accessible emergency systems in every hospital [24]. But with the end of IHI’s Save 100,000 Lives cam-

paign and its successor, the Save 5 Million Lives campaign, the momentum of broad patient safety initiatives slowed, and the spread of Condition H and similar programs appeared to stall along with it. In Australia, eagerness to comply with the standards of the Australian Commission on Safety and Quality in Health Care appears to have breathed new life into the concept of patient activation, giving rise to programs like REACH in New South Wales, CARE (Call and Respond Early) in the Capital Territory, and the widely publicized Ryan's Rule in Queensland [25–29]. In the United Kingdom, the Call 4 Concern program at the Royal Berkshire NHS Foundation Trust has also shown considerable success [30]. In the USA, however, patient-activated rapid response, while still available in many hospitals, has generally faded into the background.

Beyond Patient Activation

One reason for declining enthusiasm may be the low usage rate that characterizes patient-activated systems, which usually receive only a few calls a month and in some systems almost no calls at all [18, 31]. While this has helped allay some caregivers' apprehensions that patients would overwhelm the team with "frivolous" calls, it presents a distinct challenge to those wishing to maintain awareness of an infrequently exercised option. The reasons for low call volume are debated. Although patients may often be unsure of what constitutes a true medical emergency, the patient population in general predictably demonstrates the same ability inside the hospital as outside it to refrain from calling emergency numbers over unimportant matters. In situations of excessive underuse, poor patient education and fear of retaliation are commonly cited possibilities. When asked, however, patients just as often appear to be concerned about being seen as breaking the bond of trust in a relationship that for them can be both dependent and intimate [32, 33].

In this context, the view of patient activation as a patient right, while a crucial underlying concept, oversimplifies a complex relationship. An illustration of this complexity may be the experi-

ence of North Carolina Children's Hospital, where the first year of a carefully planned program of family activation saw only two calls directly triggered by families, while staff-activated calls increased by 50 percent. Similarly, at Cincinnati Children's Hospital Medical Center, over a period of 6 years, "family concern" was cited as a factor in nearly 6 percent of clinician-initiated rapid response calls, more than three times the total number of family-activated calls. Researchers at the two institutions speculated that an increased awareness and sense of empowerment on the part of bedside caregivers, brought on by the patient-activated rapid response system, may have increased their responsiveness to patient and family concerns [31, 34].

However they are interpreted, accounts like these are indicative of the growing attention being paid to the relationship between the patient and caregiver. The concept of patient and family engagement, and especially the publicly reported HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) patient survey, has done much to change the dynamic between patients and staff in US hospitals [35]. Hospitals now have patient experience officers (sometimes at c-suite level) and send their staff to patient experience conferences [36, 37]. Patient and family engagement, including patient advisory councils and patient involvement in hospital quality efforts, has been a significant component of the US Department of Health and Human Services' successful Partnership for Patients, a national collaborative along the lines of the Save 100,000 Lives campaign [38]. As the concept of patient and family engagement has grown and developed, patient-activated rapid response has come to be seen as part of a web of patient-centered care including such measures as unlimited visiting hours, bedside change of shift, and family-centered rounds. In addition, broader strategies like roving nurses and improvement in situational awareness have been highly successful at driving earlier intervention and reducing adverse outcomes and have been productively paired with patient-activated rapid response [33, 39–41]. Emerging technologies in continuous monitoring, mobile technology, and electronic surveillance promise to further push back detec-

tion of patient decline [42]. In this landscape, patient-activated rapid response comes to be seen as an indispensable but far from sufficient component of an integrated quality improvement program, whose possibilities continue to evolve.

The Learning Institution

Researchers have proposed that rapid response data be mined as a sensitive barometer of patient safety, and some organizations now actively analyze rapid response calls as they occur [41, 43–45]. Patient-activated rapid response, whose calling criteria nearly all involve some sort of breakdown in communication, presents an additional possibility. At Cincinnati Children’s Hospital Medical Center, where more than 25 percent of patient-activated calls cited “lack of nurse response” or “dismissive interaction from team,” Brady et al. suggested that patient-activated calls, especially those not considered to rise to a level of clinical importance, be explored for communication breakdowns and behavioral trends that could represent future safety risks [34].

One problem with these strategies is that, as Hillman et al. point out, the full effect of medical actions may not be evident until after the patient has left the hospital [43]. There is, however, one measure that is sensitive enough to capture all the points along the patient journey. That is patient and family reports—not only in real time as arbiters of their own condition but also of precipitating and succeeding events to rapid response calls, of instances in which the rapid response system should have been triggered and was not, of cases in which the safety net worked, and of cases in which it was not needed—in sum, the patient experience of care.

This is part of a larger picture. As Hillman et al. also note, only the patient can ultimately judge the effectiveness and desirability of procedures, treatments, and the quality of care that accompanied them [43]. There is also an increasing realization that patient accounts can capture serious safety issues that, for various

reasons, are not otherwise documented [46]. Even the small sample of patient accounts presented here shows themes that invite follow-up: patients who, like Curtis Bentley, deteriorate while in the ICU; patients whose deterioration is due to inappropriate treatment orders rather than failure to recognize; and the strong correlation of failure to rescue events with night and weekend care. Much light can be shed on these and other issues by listening to families’ lived experiences. It bears repeating that the very fragmentation of a system that can lead to adverse events often keeps those who work in it from seeing its larger flaws. It seems apparent that throughout the continuum of care, there are many breakdowns that are clearly visible only to the patient and family.

To patients and families, this is not an academic matter. Not surprisingly, most users want to ensure that their medical systems are safe, and an obvious first step is to share their observations with their healthcare providers. Harmed patients and families, especially, express a nearly universal desire to bring meaning from their experiences by feeling that they are part of change [47]. The structure in which this can occur is now fairly clear, if not easy, and includes both open and honest communication and patient involvement in quality improvement, including event review [48]. But while such changes are occurring, they are not occurring quickly in most organizations. Of the families in this chapter, only two—my own and Josie King’s—were able to engage in meaningful and timely discussions with the institutions where harm occurred. The aftermath of most patient stories continues to be a search for answers that in many cases are not forthcoming and a sense of deep despair when this mark of respect is denied to them.

Alyssa’s Story

I will leave the final word on this subject to a mother, Carole Hemmelgarn, whose 9-year-old daughter Alyssa died from a hospital-acquired *Clostridium difficile* infection days after being

diagnosed with leukemia. Although she now works closely with national safety and quality organizations, Carole suffered through years of distress and uncertainty when the hospital declined to offer explanations, discuss improvement, or engage with her on a personal level over the death of her daughter. Here is Carole's story.

When people think this ends ... it never ends. I got a call at 4:18 on a Monday afternoon that she had leukemia, and you know, it rocks your world because it wasn't what you were expecting.

[In the hospital] the people treating her thought she was anxious, she wasn't. She had an infection that was elevated, she was turning septic. Classic case of failure to rescue, her blood pressure was dropping, she needed oxygen, her pulse was increasing, cognitively not there, everyone thought she was sleepy...

After Alyssa died, we were in a state of shock. You took your daughter to the hospital, you came home without her. We walked into the house and had to tell her brother she's no longer alive; what happened?

It was a journey. It took them 3 years, 7 months, 28 days to have an honest conversation with me. All I ever wanted to do was know the truth, so the other people walking into the front doors of the organization would learn from the mistakes and wouldn't have to go through the same thing Alyssa did [49].

It's not something that you want to do, it's something that you have to do ... I'd rather she be here than to have to do this, but if I know someone else doesn't have to wake up to an empty bed, or sit at a kitchen table where a chair that used to be filled isn't filled any more, then we're doing a good thing to make the world a better place [50].

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