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Pediatric and congenital cardiac care and the associated outcomes have improved radically over the past generation. However, despite this improvement, treatments continue to be misused, underused, and overused, and preventable harm continues to occur. By highlighting the best practices for measuring outcomes, this book proposes a framework to help map out and support the next leap in improving pediatric and congenital cardiac care.

Major changes are needed in the current model of care delivery. Given the pressures on health-care, in order to thrive, institutions must focus on quality of care, including cost-efficiency, through innovations that align the incentives of payers, patients, and providers. Engaging clinical staff is critical to accomplishing this realignment.

With the changes in the medical and social care of children have come an uneasy and increased scrutiny and public oversight of medical practice. Improving the reliability of care will require accepting this forced transparency and embracing the opportunities inherent in this new and hyper connected and social medical driven world. In 2014, the thirst of the public for more information and

transparency, coupled with payers and regulators seeking safer and higher-value care, led both the UK and the US to expand programs of public reporting of cardiac surgical outcomes. The release of such data is just the beginning of a major international revolution to make data about the outcomes of patients and the cost of healthcare publically available and available for more effective decisions about care.

Pediatric and congenital cardiac care is a model for medicine because of its success in fostering cross-disciplinary and multi-disciplinary collaboration and has pioneered the collection and sharing of risk-adjusted data. At the heart of a sustainable, generative, and continuously improving organizational culture of healthcare is a system with three interlinked aims [1]:

- better outcomes (e.g., for individuals and populations),
- better performance of the system (e.g., higher quality, safety, value), and
- better professional development (e.g., improved work-related competence, joy, and pride).

How does the present culture and style of management of hospitals providing pediatric and congenital cardiac care support these three interlinked aims?

Organizations and communities, including those in healthcare, respond to positive and affirmative thoughts and information: “Energy flows where attention goes.” Real quality improvement requires bringing multiple systems of knowledge together. If done effectively, this combination could guide other fields in healthcare down a bold path on “how to” think different, be transparent, and emotionally and intellectually engage all stakeholders.

Mistrust in healthcare systems and among providers has contributed to cynicism, burn out, and the disengagement by clinicians. The growing pressures of an expensive and laborious system of medical liability can ultimately harm patients; the system of medical liability focuses on blame and shame, and drives defensive and sometimes perverse actions by providers and institutions. Meaningful change through learning happens at the level of discourse, and not through the courts of law. The best clues to changing the culture of healthcare will come from listening to how clinicians and staff talk about their work, organizations, colleagues, and the

joy in continuing to work and prosper as pediatric cardiovascular providers future.

If we are to receive a continuous flow of information about possible hazards, near misses, or unsafe conditions in healthcare, trust has to be (re)built and maintained in two areas. In the first, all front-line clinical and administrative staff must feel that it is *safe to identify a specific problem that may involve or uncover errors made by others* [2]. No-fault models could detoxify the present situation while compensating patients for preventable harm. This process must also include committing to full disclosure when things go awry, and establishing peer-support programs, both for clinicians as well as for patients, families, and providers involved in cases of adverse care or events. Recent evidence confirms that programs of open-disclosure based on peer support, and guided by senior clinicians who mentor and support caregivers before and during an adverse event, can improve the outcomes of patients, providers, and organizations.

In the second area, trust must be built around efforts to *ensure hierarchical and organizational transparency*. When clinicians do not feel safe or it they feel unsupported and threatened, they do not speak up about ongoing and emerging threats and consequences that undermine safe practices [3]. Avoiding difficult conversations keeps us from becoming more reliable. Without trust, clinicians tend to resist intentional change, partly because competing commitments and assumptions effectively hold the “status quo” in place. Moreover, the inability to implement change can be exacerbated by patters of work flow that incorporate “normalized deviance,” in which some processes of care have evolved over time to fit established work flow and systems, even though these practices may be viewed as “unsafe” and not sanctioned [4]. Further, if a culture of fear is contributing to normalized deviance, this will keep clinicians from doing the right thing the joy in continuing to work and prosper as pediatric cardiovascular providers [5]. The cognitive dissonance that clinicians and executives feel when confronted by organizational opaqueness is predictable and can lead to a lack of sharing of information, lack of learning, and ultimately disruptive behaviors, frustration, burnout, and high churn rates [6].

In this book, we have synthesized many of the leading theories from the clinical sciences, organizational communication, medical sociology, change management, process improvement, and public policy. We have described how these theories will advance pediatric and congenital cardiac care. Developing an inclusive and pragmatic conceptual framework of the factors that shape sharing of knowledge may help improve learning, team building, system resilience, and quality outcomes in cardiac care. This new framework is consistent with the resilience engineering model around the importance of occupational and organizational structure [7]. There are three compatibility factors in this model that can be applied to cardiac care:

- **knowledge factors** related to the epistemological differences between groups and “silos” in care; for example, how groups make sense of their work; how they understand the role of other professionals; and how meaning is articulated by managers versus by staff;
- **cultural factors** related to the shared meanings and values that shape communication; for example, when knowledge should be shared and with whom and how institutional norms, identities, and trust reinforce boundaries and hoarding of knowledge; and
- **organizational factors** related to the influence of departmental, regulatory, and institutional factors that shape sharing of knowledge, such as socio-legal rules, professional jurisdictions, organizational priorities, and constraints of resource.

Complexity theory [8] points to three types of problems:

1. **simple**, in which the relationship between cause and effect is obvious to all (e.g., placing a chest tube; an antibiotic cures a bacterial infection);
2. **complicated** (e.g., putting a patient on extracorporeal membrane oxygenation [ECMO]; diagnosing a bacterial infection); and
3. **complex** (e.g., tracing the bacterial infection to contaminated water; repairing the defective heart of a child, designing new software).

In complex settings where all the elements and interactions are not knowable, and even with a shared aim and relationships among the members of the team, adverse events may still occur.

The systems approach many authors evoke in our book draws attention to the wider organization, management, and culture of healthcare. Research has revealed, for example, that threats to safety in the acute phase (i.e., in the operating theater), subacute phase, and hospital discharge phase are shaped by inter-departmental relationships, attitudinal differences, and cultures that normalize risk. To date, however, this research has tended to focus on systems of care within confined areas and single clinical environments or organizational settings, such as settings of primary or secondary care, the operating room, the intensive care unit, and the emergency department. Little attention however has been paid to the threats to patient safety that arise when patients and information move between and across systems (microsystems) of care.

It is important to appreciate both the barriers and drivers leading to safe and reliable outcomes. These barriers and drivers are usually a complex and meshed “constellation” of factors found within and between organizational processes [9]. These barriers and drivers include:

- regulatory and media pressures;
- organizational boundaries;
- perverse financial incentives; and,
- shifting of professional responsibility.

Continuous quality improvement in healthcare requires bringing multiple systems of knowledge together and being open to constant refinement and reflection. “Good” science involves more than evidence of effect; it requires innovative methods of research, including “action research,” “expansive learning,” and other “ethno-methodologies.” These new methods can help shed light on the relationships and interactions between providers, patients, and the technologies that support and mediate this interaction. The shared benefit of these methods can lead to the active engagement of patients, providers, and the research community, working together to engender respect, trust, and collaborative relationships. This engagement will also help maintain the joy of working, nurture the passion that originally drew providers to healthcare, and reinforce the commitment of dedicated clinicians, allowing them to be courageous and compassionate.

High-reliability organizational approaches—those capable of prolonged, consistent, and

safe performance—are a hallmark of high-risk industries, outside of healthcare [10]. In the face of the growing forces of healthcare reform and increased market competition in for-profit systems, moving to high reliability requires adopting and supporting a culture of mindfulness, engagement and transparency. Such a culture will shed light on the relationship and synergy of a variety of organizational risk factors and their effect on producing harm and inefficiency. This culture strives to understand how to support mindful technologies and learning that are embedded in routine practice, and encourages norms and values that characterize high-reliability organizations, including a:

- preoccupation with preventing failure;
- reluctance to simplify operations;
- commitment to resilience; and,
- deference to sharp-end, front-line clinicians.

The engagement of clinicians occurs when it makes sense and clinicians can see that it adds value to patient care. Strategies to promote clinician engagement must [11]:

- mobilize clinicians to move and experiment within their own systems;
- provide permission, space, and time to find purpose and set directions in partnership with their patients and consumers;
- direct attention to what is happening at the level of delivery of service; and,
- facilitate respectful interaction between clinicians and managers.

Ackoff et. al. wrote about “power over” versus “power to” in regards to getting things done [12]. “Power over” is the use of authority to punish or reward. “Power to” is the use of ideas to inspire, engage, and transform front-line workers into champions of new ideas. The success of health organizations shifts from “power over” workers and patients, to “power to” from top-down management to a partnership with patients, families, and communities. Although there is little question that quality improvement and patient safety lie at the heart of a major shift in how people think about and deliver pediatric and congenital cardiac care, the shift itself will require a full generation to fully mature [13]. The foundation of this evolution in pediatric and congenital cardiac care requires an depth appreciation of the

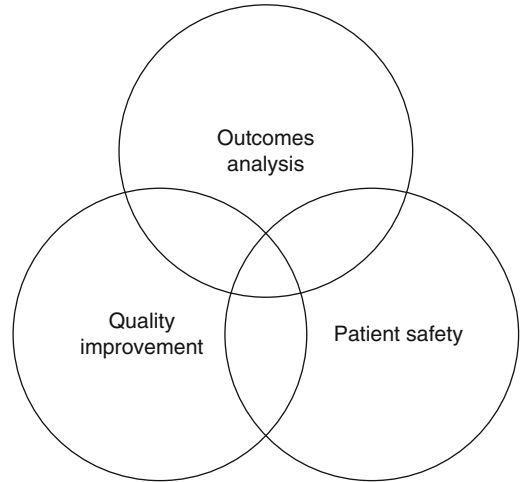


Fig. 36.1 The foundation of this evolution in pediatric and congenital cardiac care is a solid understanding of the inter-relationships of the domains of outcomes analysis, quality improvement, and patient safety

inter-relationships of the domains of outcomes analysis, quality improvement, and patient safety (Fig. 36.1) [14].

The Venn diagram (Fig. 36.1) demonstrates the close and overlapping relationships between the three domains of this textbook: outcomes analysis, quality improvement, and patient safety.

The editors feel that the ideas in this book could not be timelier, and we therefore appreciate the thoughts and wisdom from the community of experts we have assembled. These ideas present a road map: how to “think different” and how to better engage patients, clinicians, and providers emotionally and intellectually in transforming health care—the core work of this generation of committed professionals. We hope you will find this book helpful and trust you will enjoy reading it as much as we have enjoyed preparing it.

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