


# Family-centered care and acute care cardiology: borrowing lessons from other disciplines

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## Editorial

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## Borrowing lessons from other disciplines

The emerging subspecialty of paediatric acute care cardiology is increasingly recognised as an essential element of the modern heart centre's aim to improve care for children with heart disease.<sup>1</sup> Acute care cardiology facilitates complex care for children with heart disease, investment in units and inpatient infrastructure, and resource allocation. The structure of acute care cardiology allows for rapid examination and incorporation of best practices. For example, utilising practices described in surgical fields, centres with acute care cardiology tested and implemented new approaches to post-operative chest tube management, decreasing chest tube duration and length of stay.<sup>2</sup> Family-centered care is another best practice that warrants consideration as a core construct in acute care cardiology. Family-centered care is considered the gold standard for inpatient and outpatient paediatric care.<sup>3,4</sup> It is well described that family-centered care improves patient and family autonomy, which improves clinical outcomes by reframing decision-making as a collaboration with families.<sup>5–8</sup> Furthermore, family-centered rounding, the primary tangible form of family-centered care in the inpatient setting, is known to improve staff satisfaction, nursing engagement, and reduce harmful errors.<sup>8</sup> Despite these gains, family-centered care is not yet effectively operationalised in paediatric cardiology.

The systematic advantages of acute care cardiology position it to uniquely embrace family-centered care and extend its benefits to families of children with heart disease. However, before acute care cardiology can develop best practices related to family-centered care, it is necessary to address features that distinguish it from general paediatrics and may influence how family-centered care is delivered – namely, the prevalence of medical complexity, reliance upon novel diagnostic and therapeutic technologies, and staffing and structural differences of acute care cardiology units compared to general paediatrics units.<sup>9</sup> While implementation of family-centered care in paediatric cardiology requires acknowledgement of these challenges and limitations, there is reason to invest in family-centered practices.

## Informed consent demonstrates the benefits of family-centered care

In the early 20th century, autonomy was recognised as an ethical tenet and informed consent became standard practice, meant to respect patient choice and promote shared decision-making. As such, informed consent is inherently part of the broader autonomy fostered by family-centered care.<sup>5</sup> Literature on informed consent offers some guidance regarding the challenge of involving families in complex decision-making, adaptable to acute care cardiology. Informed consent requires: understanding – the ability to know the meaning of information; opportunity to express a choice; appreciation – applying understanding to one's own life; and reasoning – extrapolating consequences of and comparing choices.<sup>10</sup> Achieving all four requirements in the face of medical complexity and modern diagnostic and therapeutic technologies requires extensive clinician-patient/family discussions built on an ongoing professional relationship.<sup>10</sup> These requirements are also applicable to broader decision-making during acute care cardiology hospitalisations. Through family-centered care, acute care cardiologists are ideally positioned to build this ongoing therapeutic alliance.

While informed consent offers a model for family-centered care, there is a need for expertise in the exchange of information such that its purpose does not devolve into exclusively serving as legal protection for clinicians.<sup>11</sup> The gap between effective knowledge transfer/patient understanding and signed informed consent forms is evidenced by the frequency of lawsuits with patient claims of inadequate understanding of one or more aspect of informed consent.<sup>12</sup> This has highlighted the need for senior-level clinician discussion regarding complex care decisions. In Pennsylvania, the Supreme Court found informed consent to be a non-delegable physician activity and must be performed by the attending (*Shinal v. Toms*, 162 A.3d 429 (Pa.2017)). While not universal, this ruling shows that having the most knowledgeable clinician at the

bedside for patient communication is fundamental to the information transfer needed for patient autonomy, informed consent, and family-centered care. Within paediatric cardiology, acute care cardiologists are ideally suited to fill this role, utilising the tools of family-centered care as patients proceed through hospitalisations and are presented with care decisions.

### Diagnostic and therapeutic complexity and family-centered care

One challenge to implementing family-centered care in paediatric cardiology is difficulty explaining highly specialised diagnostic data and therapeutic options. In national surveys, hospitalists report significant barriers to delivering family-centered care to children with medical complexity.<sup>13</sup> The complexity of disease and offered interventions makes it difficult to get families “up-to-speed,” hindering families’ ability to participate meaningfully in shared decision-making.<sup>14</sup> These challenges are arguably worse among families of children with cardiac disease who report higher levels of confusion related to inpatient stays than “all-comer” paediatric families, highlighting the need for expertise in communication through family-centered care.<sup>15</sup>

The genetics literature offers insight into the challenge of communicating complex diagnostic data, particularly where there is uncertainty. Genetic testing requires integrating families into decision-making regarding complex technology with life-altering implications and unknowable potential risks.<sup>16,17</sup> Considering that clinicians themselves cannot be aware of all downstream implications of genetic testing, there are significant challenges in getting patients “up-to-speed”, inherently impacting their ability to make fully informed decisions.<sup>18</sup> To address this, genetics literature and clinical practice models highlight a need for real-time “translators” of genetic information as it is applied in clinical decisions. Genetic counsellors, now integral in genomic medicine, have emerged to fill this expert, translator role.<sup>19</sup> Here again, acute care cardiology expertise offers the opportunity to cultivate this “translator” role in concert with the family-centered approach. As in genetics, it is necessary in acute care cardiology to make sense of specialised technologies, including advanced clinical imaging, interventional cardiac procedures, and complex polypharmacy.

### Family-centered care in acute care cardiology

Acute care cardiologists are uniquely positioned to address the challenges described above – to serve as “translator” of complex technologies and knowledgeable bedside clinician necessary for the information transfer integral to family-centered care. Acute care cardiology is fundamental to bringing family-centered care to the focus of complex cardiology care decisions, as hospitalists have within general paediatrics and internal medicine.<sup>3</sup> As those fields have learned, adoption of family-centered care improves patient outcomes and family and staff satisfaction.<sup>8</sup>

A formalised plan for implementing family-centered care in acute care cardiology is needed. One approach may be adoption of family-centered rounding, through which medical teams partner with families for daily decision-making on acute care cardiology units – units with staff, beds, work-flows, and unit policies dedicated to the care of children with congenital and acquired cardiac disease. Despite widespread adoption of family-centered rounding in paediatrics, adoption in subspecialty care has been limited because of conflicting demands on specialty clinician time and family-centered rounding can be time-intensive.<sup>3,4,20</sup>

However, acute care cardiologists could embrace their role as content experts and effective “translators” of inpatient paediatric cardiology details. Implementation of family-centered rounding in acute care cardiology practice, will likely lead to increased knowledge transfer and improved care, as it has in other disciplines. Many outcomes used to evaluate acute care cardiology (length of stay, readmission, discharge efficacy) are directly impacted by communication with families suggesting clear targets where the benefits of family-centered care should be tested.<sup>3</sup> While a number of mechanisms exist to achieve these outcome aims, alignment with the Pediatric Acute Care Cardiology Collaborative (PAC<sup>3</sup>) to test benefits of family-centered care appears opportune.

As family-centered rounding practices are developed within the context of acute care cardiology, there is also opportunity to address challenges this rounding methodology has presented in other fields. Specifically, family-centered rounding is vulnerable to the reliability of families being at the bedside and choosing to participate. Numerous reasons exist for why families may not be at the bedside during rounding hours or may not want to participate, many of which tie into other social determinants of health.<sup>21,22</sup> It is essential that existing inequities are not exacerbated or perpetuated by inadequate inclusion of certain families. Technology solutions exist to engage families in rounds, even when not physically present. Similarly, messaging options for family/care team asynchronous communication must be enabled for families who are unavailable during rounding hours.

The perceived time consumption of family-centered care, and in particular family-centered rounding, is another known challenge. It is unknown whether family-centered rounding is more time consuming than other models of rounds; studies have shown encounters last 3–23 minutes with an average of 10 minutes.<sup>8</sup> Proponents of family-centered rounds argue this time is an investment with the dividend being improved understanding of the daily plan among the care team, including the bedside nurse and family, which presumably decreases time spent clarifying or answering questions later in the day. Here too, acute care cardiologists have an opportunity to create practices which balance communication and shared decision-making with other duties of care that occur outside of rounds.

There is increased awareness of the need for acute care cardiologists but there remains significant variability in the practice, structure, and staffing of inpatient non-intensive care cardiology.<sup>1,9,23–25</sup> Successful implementation of family-centered care requires resources, training, and expertise.<sup>3</sup> A necessary role that is emerging within cardiology, but needs formalisation, is that of the acute care cardiologist: the attending cardiologist responsible for the care of inpatient children with heart disease who do not require critical care. In addition to providing clinical and infrastructural expertise for delivery of inpatient care, the acute care cardiologist would be available at the bedside, able to dedicate time to and skilled in family-centered care, serving as the “translator” of multiple facets of coordinated, complex care for these children. Just as hospitalists have utilised family-centered care to improve outcomes and process measures in paediatrics and internal medicine, acute care cardiologists can usher the use of family-centered care in cardiology to achieve the same benefits.

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## References

- Anderson JB, Chowdhury D, Connor JA, et al. Optimizing patient care and outcomes through the congenital heart center of the 21st century. *Congenit Heart Dis* 2018; 13: 167–180.
- Bates KE, Connelly C, Khadr L, et al. Successful reduction of postoperative chest tube duration and length of stay after congenital heart surgery: a multicenter collaborative improvement project. *J Am Heart Assoc* 2021; 10: e020730.
- Committee on Hospital Care, Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics* 2012; 129: 394–404.
- Jaberi AA, Zamani F, Nadimi AE, Bonabi TN. Effect of family presence during teaching rounds on patient's anxiety and satisfaction in cardiac intensive care unit: a double-blind randomized controlled trial. *J Educ Health Promot* 2020; 9: 22.
- Ho A. Taking family-centered care seriously. *Am J Bioeth* 2020; 20: 65–67.
- Weingart SN, Zhu J, Chiappetta L, et al. Hospitalized patients' participation and its impact on quality of care and patient safety. *Int J Qual Health Care* 2011; 23: 269–277.
- Kambhampati S, Ashvetiya T, Stone NJ, Blumenthal RS, Martin SS. Shared decision-making and patient empowerment in preventive cardiology. *Curr Cardiol Rep* 2016; 18: 49.
- Destino LA, Shah SS, Good B. Family-centered rounds: past, present, and future. *Pediatr Clin North Am* 2019; 66: 827–837.
- Harahsheh AS, Kipps AK, Hart SA, et al. High acuity therapy variation across pediatric acute care cardiology units: results from the pediatric acute care cardiology collaborative hospital surveys. *Pediatr Cardiol* 2021; 42: 1074–1081.
- Cocanour CS. Informed consent-It's more than a signature on a piece of paper. *Am J Surg* 2017; 214: 993–997.
- Simonds VW, Garrouthe EM, Buchwald D. Health literacy and informed consent materials: designed for documentation, not comprehension of health research. *J Health Commun* 2017; 22: 682–691.
- Grauberger J, Kerezoudis P, Choudhry AJ, et al. Allegations of failure to obtain informed consent in spinal surgery medical malpractice claims. *JAMA Surg* 2017; 152: e170544.
- Adame N, Rocha ME, Loudon C, Agrawal R. Pediatric hospitalists' perspectives on the care of children with medical complexity. *Hosp Pediatr* 2011; 1: 30–37.
- Toomey SL, Chien AT, Elliott MN, Ratner J, Schuster MA. Disparities in unmet need for care coordination: the national survey of children's health. *Pediatrics* 2013; 131: 217–224.
- Pagel C, Bull C, Utley M, et al. Exploring communication between parents and clinical teams following children's heart surgery: a survey in the UK. *BMJ Paediatr Open* 2019; 3: e000391.
- Gyngell C, Newson AJ, Wilkinson D, Stark Z, Savulescu J. Rapid challenges: ethics and genomic neonatal intensive care. *Pediatrics* 2019; 143: S14–S21.
- Ayuso C, Millan JM, Mancheno M, Dal-Re R. Informed consent for whole-genome sequencing studies in the clinical setting. Proposed recommendations on essential content and process. *Eur J Hum Genet* 2013; 21: 1054–1059.
- McGuire AL, Beskow LM. Informed consent in genomics and genetic research. *Annu Rev Genomics Hum Genet* 2010; 11: 361–381.
- Deutch N, Soo-Jin Lee S, Char D. Translating genomic testing results for pediatric critical care: opportunities for genetic counselors. *J Genet Couns* 2020; 29: 78–87.
- Knoderer HM. Inclusion of parents in pediatric subspecialty team rounds: attitudes of the family and medical team. *Acad Med* 2009; 84: 1576–1581.
- Parente V, Stark A, Key-Solle M, et al. Caregiver inclusivity and empowerment during family-centered rounds. *Hosp Pediatr* 2022; 12: e72–e77.
- Anttila A, Rappaport DI, Tijerino J, Zaman N, Sharif I. Interpretation modalities used on family-centered rounds: perspectives of Spanish-speaking families. *Hosp Pediatr* 2017; 7: 492–498.
- Mott AR, Neish SR, Challman M, Feltes TF. Defining pediatric inpatient cardiology care delivery models: a survey of pediatric cardiology programs in the USA and Canada. *Congenit Heart Dis* 2017; 12: 294–300.
- Hoerst A, Bakar A, Cassidy SC, et al. Variation in care practices across pediatric acute care cardiology units: results of the Pediatric Acute Care Cardiology Collaborative (PAC(3)) hospital survey. *Congenit Heart Dis* 2019; 14: 419–426.
- Willis AJ, Hoerst A, Hart SA, et al. The added value of the advanced practice provider in paediatric acute care cardiology. *Cardiol Young* 2021; 31: 248–251.