

VIEWPOINT

Family-Centered Care and High-Consequence Pathogens

Thinking Outside the Room

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Can we protect ourselves? Can we protect our community? With the emergence of the Ebola virus outbreak, these questions have captured the attention of the American audience; however, these issues are hardly new to the US health care system. Caring for individuals with presumptive or confirmed pathogens of high consequence, such as Ebola virus, Middle East respiratory syndrome coronavirus, pandemic influenza, and severe acute respiratory syndrome, to name a few, provokes not only technical but also ethical dilemmas to our current health care infrastructure. While we mostly understand the science of infectious disease transmission and recognize that intensive medical care generally improves outcomes, what remains less certain is how to provide supportive care safely and compassionately. This is especially apparent in the care of a vulnerable infected child. Parents are often encouraged to aid in hands-on care of their hospitalized child, making parental presence the cornerstone of family-centered care. However, in suspected or confirmed cases where pathogens are of high consequence, we posit that parental presence may pose significant risk to the patient, parents, health care professionals, and public. We believe infections with high-consequence pathogens fundamentally alter our risk-benefit calculus and that, in these scenarios, temporary physical separation of the infected child from parents is the most effective option for safe care delivery. We challenge the pediatric medical community to view patient isolation and parental separation not as a threat to family-centered care but rather as an opportunity to reflect on our care provision, foster innovation and creativity, and cultivate a new sensitivity in family centeredness.

Family-centered care respects each child and family's innate strengths and cultural values and views the health care experience as an opportunity to build on these strengths.¹ However, in situations where infectivity or the risk of an adverse outcome with transmission is high, safety should be a guiding principle. It is from this unique perspective that we view the interaction between family engagement and infection prevention and control. Parental presence and participation in bedside care are encouraged in resource-endowed settings,² whereas family members assume the role of bedside nurse in resource-challenged settings. In resource-endowed settings where personal protective equipment is plentiful, researchers have assessed the effect of infection prevention practices on the delivery of family-centered care, mostly noting findings related to social isolation.³ The converse, evaluation of the effect of parental pres-

ence on infection prevention practices, has not been a focus of study.

The management of high-consequence pathogens in children offers a unique set of infection control challenges. If parental presence is endorsed, should parents be required to don and doff personal protective equipment (PPE)? Which hospital staff members should enforce PPE training, compliance, and other prevention practices, such as postexposure prophylaxis, when indicated? How is a breach in isolation handled? Who assumes responsibility should a transmission occur? Should PPE be allocated to family members when supplies are limited? Given that the isolation of children with these infections would be protracted, should practices differ when risk of transmission is greatest? As many centers propose an additional health care professional in the room to assist with the care of children who are developmentally unable to cooperate, would adding a parent create an additional safety risk to the child, parent, and staff? Cultural and language barriers are a recognized challenge in infection prevention counseling in ideal settings. Given the need to depend on interpreter services, how can effective counseling regarding PPE be ensured? These difficult questions illustrate infection prevention complexities.

Even if appropriate PPE and infection control practices could be implemented for a parent, this may serve as a barrier between parent and child. Lessons from severe acute respiratory syndrome have taught us that wearing masks inhibits effective communication.³ Reduced auditory and visual cues among wearers of PPE limit health care professional to patient and parent to child interactions. How likely would a child be to recognize his or her parent in PPE? We recognize that PPE can create psychologically and physically detrimental barriers between child and professional. We maintain that a physical barrier is both necessary and critical for the protection of all in cases of high-consequence pathogens.

Opponents may argue whether parental PPE is necessary given that parents are often coexposed to the source of infection and have contact with their own infected child. Here, we can draw the following point of distinction: in ambulatory and emergency department settings where the majority of health preparedness guidelines traditionally focus, we recognize that enforcing parental separation could be a difficult task. However, in confirmed or highly suspected cases requiring care in an intensive care or biocontainment unit, we know that transmission can be prevented with meticulous PPE use by highly trained essential professionals. Cohorting infected or presumptively infected children

and parents outside the newborn period is unlikely to be an option. Moreover, preventing additional exposure to parents will ultimately protect health care workers who will be called on for the subsequent care and monitoring of these high-risk potential patients.

We acknowledge that prevention strategies for high-consequence pathogens may create perceived barriers to family-centered care; however, we urge the medical community to shift their attention to the implementation of alternative strategies that harness family centeredness but also mitigate overall risk. Extrapolating from lessons of geographic separation, several qualitative accounts attribute success to the use of videophones and web-based media.⁴ Repurposing technology used for communication between health care professionals that is already in use can create virtual parental presence and reduce both parent and patient emotional isolation. Several family members could make use of videophone technology, casting a broader net of support than may otherwise be provided with parental presence. If videophone technology is not available, cellular telephone communication, email, or digital notes/pictures can be used to ease separation anxiety.³

Making the best use of other hospital services will be an integral part of care coordination. Using chaplains/religious services, patient advocates, and ethics consultative services can be especially helpful in sensitive case-based situations. Child life specialists can

aid in disseminating developmentally appropriate education and prevention messages to patients, parents, and siblings and can provide support to staff. Engaging family members in rounds and patient care discussions with a consistent, designated physician is the foundation of family-centered care and can be done in any physical or virtual location.

Lastly, we recognize that limiting parental presence places additional responsibilities on health care professionals to provide emotional, psychosocial, and medical support. High-stake situations often incur such forced role change, and pediatric professionals are more than able to assume this role.³

We propose cultivating a new role in family centeredness in the setting of high-consequence pathogens. Optimizing virtual technology, having health care professionals assume an active role in family centeredness, and thinking creatively will facilitate the provision of safe and effective care. As infection control specialists, we seek to leverage our role as advocates for both child and public health. We do not disagree or challenge the value of family-centered care but rather aim to open a nuanced dialogue about the ethical implications of clinical scenarios involving high-consequence pathogens. We prioritize the safety of patients, their families, and our health care workers first, and, in doing so, we are open to broadening the definition of family-centered care. We hope that all pediatric health care workers follow suit.

ARTICLE INFORMATION

Published Online: September 14, 2015.
doi:10.1001/jamapediatrics.2015.1753.

Conflict of Interest Disclosures: None reported.

Additional Contributions: We acknowledge the guidance and support of the Society for Healthcare Epidemiology of America's Pediatric Leadership Council, especially Chris Nyquist, MD, MSPH, Children's Hospital Colorado; Lisa Saiman, MD, MPH, Columbia University Medical Center, New York-Presbyterian Hospital; Angela H. Rupp, MT, MS, CIC, Ann & Robert H. Lurie Children's Hospital of Chicago; Judith Guzman-Cottrill, DO, Oregon

Health Sciences University; Caroline Quach, MD, MSc, The Montreal Children's Hospital; Jane Gould, MD, St Christopher's Hospital for Children; Donna Fisher, MD, Baystate Children's Hospital; and Meera Varman, MD, Creighton University Medical Center.

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