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SPECIAL ARTICLE

**Abstract:**

The Ebola virus disease (Ebola) outbreak in West Africa (2014-2015) prompted domestic planning to address the scenario in which a traveler imports Ebola into the United States. Parental presence at the bedside of a child with suspected or confirmed Ebola emerged as a challenging issue for pediatric health care providers and public health practitioners. At the heart of the issue was the balance of family-centered care and appropriate infection control, which are not easily aligned in the setting of Ebola. In the following dialogue, pediatricians, who participated in discussions about parental presence during the evaluation of pediatric persons under investigation, and a public health ethicist discuss the interplay between family-centered care and appropriate infection control. Reaching a balance between the 2 ideals is difficult and may require the facility and providers to engage in a deliberate conversation to determine how they will handle parental presence for such high-risk scenarios, including Ebola and other high-consequence pathogens, in their institution.

Keywords:

Ebola virus disease; infection control; family centered care; bioethics

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Parental Presence at the Bedside of a Child with Suspected Ebola: An Expert Discussion

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The Ebola virus disease (Ebola) outbreak of 2014-2015 in West Africa prompted widespread domestic planning in the United States focused on the possible importation of Ebola from a traveler arriving from an affected country. Travelers from West Africa included children, and guidance was developed to address infection control considerations in school settings¹ and during pediatric patient transport by emergency personnel.² However, parental presence at the bedside of a child

for Science, Atlanta, GA; #Centers for Disease Control and Prevention, Center for Global Health, Office of Public Health Preparedness and Response, Atlanta, GA; **Centers for Disease Control and Prevention, Office of Public Health Preparedness and Response, Atlanta, GA. Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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suspected of having Ebola emerged as a difficult issue for pediatric health care providers, as they sought to balance the goals of family-centered care with those of appropriate infection control. In a family-centered care model, maintaining the integrity of the family unit is paramount. The family serves as a source of strength and support for the child's recovery, and the child is a source of strength and resilience for the family.³⁻⁵ Infection control protocols, however, specifically focus on preventing the spread of disease; the safety of health care workers (HCWs) and patients, other family members, and the community takes precedence.⁶

To explore parental presence at the bedside of a child with suspected Ebola in the United States, we invited subject matter experts to discuss a fictional case study from the perspective of family-centered care or infection control. The subject matter experts are pediatricians who participated in discussions about parental presence during the evaluation of pediatric persons under investigation and a public health ethicist. The intent of the expert discussion is to explore the issues surrounding parental presence that were identified during the domestic response to the 2014-2015 Ebola outbreak, not to identify a standard of care.

THE CASE

A family returned from a country with widespread transmission of Ebola during the peak of the

outbreak. The family had no contact with a known individual with Ebola and did not attend a burial or funeral while in-country, and all family members were asymptomatic when screened at a US airport. A 2-year-old male becomes symptomatic 1 week after returning to the United States; the parents are asymptomatic. The parents transport their child to a pediatric hospital that is a designated Ebola treatment center. The local and state health departments are notified. His symptoms include a fever of 103°F, nonbloody diarrhea, vomiting, and moderate dehydration. The parents wish to remain at his bedside during his evaluation and also insist that they will remain at his bedside even if he tests positive for Ebola.

INITIAL EVALUATION OF THE CHILD

Steven Krug (SK), Pediatric Emergency Medicine: Upon presentation to the emergency department (ED) triage desk, I would hope the patient's presenting complaints, parental concern, and screening questions that are now part of our standard triage assessment would prompt recognition that this child (and any accompanying family members) may have been exposed to Ebola, with the presenting complaints potentially representing early symptoms of disease. The patient and family would be moved immediately to one of our ED isolation rooms or, if no room was available, to an empty consult or conference room. Once placed in an appropriate exam room, the index patient and immediate family (1 or 2 parents) would be asked to remain in that room, with additional family members and others accompanying the patient placed in a nearby family room, and staff would be assigned to ensure compliance. Hospital infection control and the Department of Public Health would be immediately notified.

In this scenario, a patient brought by a family to the ED, the parents would be permitted to remain in the examination room until it became time to move the child to the location in the hospital (pediatric intensive care unit [PICU]) where she/he would remain until cleared of having Ebola or until treatment of actual Ebola disease was complete. Of note, patients being transferred to our hospital with advance notification by the Department of Public Health would bypass the ED and go directly to the PICU treatment area. This bypass was created in an effort to limit the number of staff exposed and exposure risks for patients and families in public areas.

Susan Hoocevar (SH), Pediatrician, Infection Control: An ill toddler with vomiting and diarrhea can be difficult for health care workers to care for under the

best of circumstances, and parental help is often used. The potential for Ebola raises unique considerations for the standard of parental presence at the bedside. In situations such as this, the facility would first need to consider the parent's travel, exposure, and symptom history in coordination with public health authorities before allowing access to the hospital.⁷ Access to the facility was granted in this instance, so infection control staff must now consider how the parents' movement while in the facility will be constrained because of exposure to the symptomatic child. Hospitals are public places visited by many people daily; if a parent were to become ill while at the facility, the potential of exposure to the general public and hospital staff would be worrisome, necessitating that the facility develop procedures to counter such risk.

Aaron Milstone (AM), Pediatric Infectious Disease: Given the public health impact of Ebola, taking precautions during the evaluation of this child is appropriate to protect health care workers from potential exposure. Parents and the child may pose an exposure risk to health care workers, as parents may not disclose symptoms in fear that they will be separated from their child. Fortunately, our experience to date suggests that this child likely does not have Ebola, but further evaluation and testing are appropriate. This child should be considered low risk for Ebola given travel to a country with widespread transmission but no direct contact with a known Ebola-infected individual. Therefore, it seems reasonable to allow the parents to remain with the child during the initial evaluation. Parents should be informed that the initial evaluation may take more than 24 hours to determine if testing is necessary or to make arrangements for hospital admission. During the evaluation, the parents should be restricted from visiting common areas in the hospital or returning to the waiting room. Keeping the parents in an isolation room with the child during the evaluation may reduce potential exposures if the parent subsequently reports Ebola symptoms. If and when a parent is with the child, the parent should wear personal protective equipment (PPE) (at minimum a mask, disposable gown, and gloves) to reduce risk of ongoing exposure, and ideally, the parents should be instructed on how to put on and take off PPE and safely handle bodily fluids.

HOSPITALIZATION AND/OR FURTHER EVALUATION AND MANAGEMENT OF THE CHILD

Dele Davies, Pediatric Infectious Disease: The primary issues are minimizing fear and anxiety in

this toddler (person under investigation [PUI]) with no known exposure to Ebola while at the same time minimizing the risk of transmission if confirmed to have Ebola. The institution's ability to quickly rule out Ebola and other possible conditions, such as influenza, typhoid, or malaria, is also important, as it may help determine duration of caregiver presence. Given the age of the PUI, presence of a known caregiver would be a source of important psychosocial comfort and reassurance to the child and may enable more effective nursing care. Given the fact that all family members have been together, there is a strong likelihood that any exposure has already been shared between the caregiver and this PUI. Thus, the caregivers' stated intent to stay with the child warrants consideration, and forcibly separating them could cause high levels of stress for both the patient and family. In the absence of a caregiver, the care may also be perceived differently by the family, increasing the risk of medicolegal liability for staff and the facility. Although other means of communication, engagement, and other child life measures may be enough to reassure an older PUI without caregiver presence, this may not be adequate for a toddler. Allowing presence of the caregiver demonstrates to the family that the health care organization values their involvement in the child's care. If the caregiver is willing and able to adequately comply with procedures and clearly understands and accepts the risk, denying them access to their child may be viewed as morally questionable or paternalistic. Maintaining the caregiver-child interaction while the child is under investigation could also allow time for training in PPE use and other hospital procedures.

On the con side, there is a risk of a more intimate interaction of a toddler with the caregiver, which may translate to a greater risk of caregiver exposure to bodily fluids and Ebola, if they had somehow not been previously exposed. The caregiver may then increase the risk of exposure of other HCWs, family members, and the community. The potential loss of this caregiver in time spent away from the family in caring for the PUI may add significant stress to the family unit. Furthermore, the presence of the caregiver may also interfere with nursing/provider care of the PUI in case of an emergency. To mitigate these concerns, the caregiver's presence should be strictly for emotional support. Practices that could increase the likelihood of contact with body fluids, such as diaper changes, would have to be strictly forbidden. There would have to be a demonstration of caregiver understanding of informed consent, and sufficient mental and physical capacity to follow instructions. There would also need to be close

assessment and monitoring to ensure that they use PPE appropriately. It is unclear how the toddler PUI would respond emotionally to the potentially sudden and mandatory departure that may be needed as a result of caregiver discomfort following wearing PPE for 1 to 3 hours. Even with the probable low risk, it would be ethically hard to justify having a pregnant caregiver present in the room given the known poor outcomes if infection occurred. Also of concern is who would ultimately be deemed responsible for the risk taken by the caregiver if they become infected because of exposure in the facility. Anonymity of the caregiver and their movements and communication of safety to the other patients and their families would be paramount to avoid anxiety and possible hysteria. The recent dramatic success of the recombinant vesicular stomatitis virus (rVSV)-vectored Ebola virus disease vaccine in preventing secondary spread may offer a level of comfort to parents and caregivers in minimizing risk of secondary spread while allowing parental presence.⁸

AM, Pediatric Infectious Disease: Beyond the initial evaluation, the risks of parental presence for a child with Ebola outweigh the benefits. In the case of suspected Ebola, separation should be considered: (1) to protect the parent, and (2) to reduce the risk of the parent exposing others. Parents cannot be quickly trained to remain in the room and participate in the care of the child in a way that will protect them from ongoing exposure and disease. It is not practical to expect a parent to wear enhanced PPE 24 hours a day for several days. If the child is diagnosed with Ebola, then the parents will be considered high-risk exposed individuals who could place others at risk when they leave the child's room. The hospital may not have the functional capacity for a parent to permanently reside in the room (without leaving to shower, use the bathroom, eat, etc). Local health department should be involved in decisions regarding management of high-risk exposure parents who pose a public health risk.

Health care workers who care for Ebola patients may inadvertently be exposed and are risking their lives to help others. Allowing parents to place themselves in harm's way and potentially get Ebola places an additional burden on HCWs who will be asked to care for the parent if they developed Ebola. Although we empathetically may want to let the parent remain with the child, we must protect parents, our HCWs, and the public. Technology, such as video conferencing, should be made available to foster the parent-child interaction. Child life or other trained providers should be available to support both the child and the parents. Facilities will need to be prepared for a high staffing

level to support the needs of the child separated from their family. The perceived benefit a parent might play in supportive care of the child seems outweighed by the risk an "exposed" parent poses to HCWs and the public.

SH, Pediatrician, Infection Control: In this scenario, the recommended PPE⁹ is complex, is cumbersome, and requires repeated trainings to develop competency in its utilization. The parent would not be able to enter the room without proper PPE; it is impossible to assert with full confidence that the parent has already had an exposure that would result in disease transmission and, therefore, would not be in need of PPE. Just in time training and fit-testing (depending on the components of PPE chosen by the facility) of a parent for this particular PPE ensemble would be extremely difficult to successfully execute and require intensive HCW support. While in the room caring for the patient, the HCW must be focused on the task at hand of caring for a patient with potential Ebola. The presence of a parent could prove to be distracting, creating the potential for unrecognized exposures for the HCW. Furthermore, the care environment in the rooms designated as Ebola treatment areas, in most facilities, is limited in size, making the addition of extra people a safety concern. Maneuvering in PPE becomes more difficult with limited space, creating an environment where falls or inadvertent catchment of PPE on equipment creates the potential for breaches to occur. Upon exiting the room, a careful and practiced doffing procedure must ensue to avoid self-contamination. A parent will need assistance in this scenario, requiring additional staff support; this would likely occur several times per day given the need to perform activities of daily living (eg, eat, sleep, shower) and the inability to do these things while in the patient care area. HCWs could be exposed while assisting an inexperienced person with doffing. Contamination of the clean hospital environment (ie, the area outside of the patient care area) by a parent could occur because of unrecognized breaches in PPE or difficulties in the doffing procedure, placing HCWs, other patients, and visitors at risk for exposure. This scenario highlights the complexity of caring for a patient with potential or confirmed Ebola. The stress placed on the HCWs and broader facility systems while trying to adhere to complicated infection control procedures is immense. In each scenario, the added complexity of an untrained parent in the room may further stress the system as well as HCWs and should be considered carefully.

SK, Pediatric Emergency Medicine: There has been substantial debate within our institution

regarding the merits of family-centered care and parental presence—standard practices in care delivery throughout our hospital—vs the inherent risks posed by the presence of family who likewise may have been exposed or could become exposed during the course of care. Of particular concern would be the increased risk of exposure for hospital staff, other patients and their family members, visitors, and the community at large. In efforts to prepare to care for an Ebola patient, our organization learned that it is challenging to ensure appropriate training and ongoing skill maintenance among clinical staff for the safe donning and removal of PPE. We determined that we could not reasonably expect sufficient training and observation of PPE use and consistent performance of safe infection control practices among family members. The outcome of this very difficult deliberation was the decision to not permit family presence for these patients in our PICU. In coming to this decision, the interests/needs of the individual patient and family were deemed to be secondary to our obligation to protect the health and well-being of other patients and their families, hospital staff, and our community. Beyond this ethical framework, there also was concern for substantial liability if there was transmission of disease. For the case study, we would leverage technology to support direct communication with the family members and their virtual presence.

ETHICAL CONSIDERATIONS

Leonard Ortmann, Public Health Ethicist: The case and the expert commentary display a profound tension between the family-centered care and infection control perspectives. Both perspectives, interestingly, go beyond the normal medical perspective of focusing on the individual patient, so for that reason may pose challenges to medical staff. The family-centered care perspective looks at social relations and bonds as things that enhance care, whereas the infection control perspective looks at social relations and social contact as potential sources of harm. This situation poses a genuine ethical dilemma in that following standard family-centered care procedures arguably increases the potential for transmission of the infection, whereas prioritizing infection control procedures arguably restricts family interactions and thus works against the goal of maintaining family integrity. Because the respective goals tend to work against each other, finding a balance between them may prove inherently difficult and might necessitate thinking outside the box of standard practices by invoking an emergency preparedness mindset. It is important to

recognize that whatever level of risk is established on the best evidence available, the perception of what that risk means in practice will depend on how much people value safety in relation to, say, parental rights, liberty, or the benefits of family care. Proportioning the risks and safety concerns to parental rights, liberty, or infection control, then, may necessitate a judgment call that depends on prioritizing certain values, procedures, or perspectives that a transparent deliberative process that engages relevant stakeholders could facilitate.

SUMMARY

The experts' responses to the case study demonstrate the challenges and weighing of risks and benefits involved in the consideration of parental presence at the bedside of a child suspected of having Ebola. A number of factors may influence the decision to allow a parent or caregiver to remain at the bedside, including the clinical judgment of actual risk of infection, the child's age and level of development, where they are in their course of evaluation and treatment (initial evaluation vs hospital care), and the estimate of risk of exposure to the HCWs and the community. As experts noted, the actual risk for the child in the case study was low. However, facilities have triggers that initiate standard operating procedures for a suspected case despite a "low-risk" determination. In all cases, a balance must be sought between risk, family-centered care, and appropriate infection control. This balance between dichotomous ideals is difficult and may require the facility and stakeholders to engage in a deliberate conversation to determine how they will handle such scenarios in their institution before the appearance of another high-consequence pathogen. **+**

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